ETHICAL DILEMMA RESOLUTION: IS AGE A FACTOR IN LIFE SUPPORT CHOICES

By

JERI KATHERINE COOPER

Bachelor of Science
Oklahoma State University
Stillwater, Oklahoma
1976

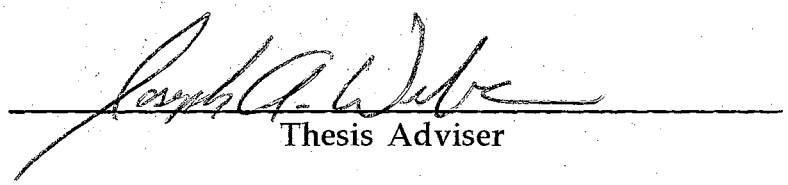
Master of Science
Oklahoma State University
Stillwater, Oklahoma
1978

Bachelor of Science in Nursing
The University of Tulsa
Tulsa, Oklahoma
1984

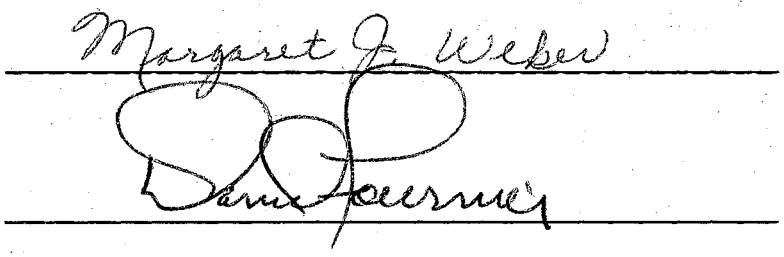
Submitted to the Faculty of the
Graduate College of the
Oklahoma State University
in partial fulfillment of
the requirements for
the Degree of
DOCTOR OF PHILOSOPHY
December, 1997

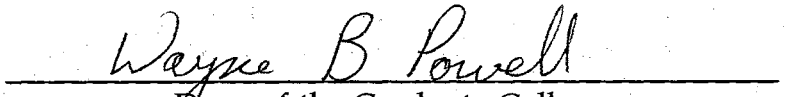
ETHICAL DILEMMA RESOLUTION: IS AGE A FACTOR IN LIFE SUPPORT CHOICES

Thesis Approved:



Thesis Adviser





Dean of the Graduate College

ACKNOWLEDGMENTS

A project which takes over four years to complete cannot possibly be undertaken alone. Along the way, I hope I have expressed my sincerest appreciation and gratitude to all faculty, friends, family and colleagues who have shown their support.

For her entire life, my mother, Amelia Smith, has had to share the spotlight with others. This time, hers will be the only name on the page.

So, for believing in the dreams of a nine year old for the past thirty years, thanks, Mom. This one's for you.

TABLE OF CONTENTS

Chapter Page

Chapter Page

CHAPTER I

INTRODUCTION

Recent advances in medical technology have contributed to the current age wave (Dychtwald and Flower, 1990). Dychtwald and Flower (1990) state that the fastest growing segment of the population is the over 65 age group, with the fastest growing portion of that cohort being the over 85 year olds. Each and every day, thousands of these senior citizens check in to America's hospitals, some electively and some emergently. When they do, they are transported into a world of futuristic life sustaining technology which engenders previously non-existent ethical dilemmas. Treatments and procedures that were mere blueprints only five years ago are today saving and prolonging lives and are being eclipsed by second and third generations of their line. Employing more procedures, better equipment, and faster cures seems to be the way all patients are treated, from those in utero to centenarians drawing their last breaths.

Significance of the Problem

Unfortunately, our societal code of ethics, medico-legal precedents and our own familial interactions have fallen short of keeping pace with bioscience. For example, there is the physical capability to undertake coronary bypass surgery on an 85 year old patient but the certainty of the moral rightness of using resources in this way, as well as the assessment of the impact on the patient and family have been sorely neglected. In a race to promote life at all costs, society has failed miserably to ascertain what those costs might be.

Ethical questions arising from the impact of increased technology include whether to initiate and when to terminate life support; who will make those decisions, patients, physicians, families, or a combination; how should scarce medical resources be allocated; and, as an embarrassing afterthought, who will pay for decisions made? Another ethical issue of note is whether the ill person deserves exclusive consideration, rather than simply special consideration. Illnesses today are of a much longer duration with patients being kept alive for months and even years at tremendous economic and emotional cost to the family and to society. In the old paradigm, patients quickly got better or died and medical costs did not require extinguishing the family savings as well as the extensive use of societal resources.

At the core of these ethical questions is the Western philosophy of individual autonomy and the American ideal of the right of all persons to access the best technology has to offer. The framers of the U.S. Constitution were quite clear on the principle of autonomy. The fourteenth amendment provides in logical sequence that life first, and then liberty should be given substantive, procedural and equal protection of the law (Marzen, 1994). Had there not been a technological explosion of miracle drugs, ventilators, surgeries, and artificial feedings, people would, as they have since time began, be deprived of their life only by natural means.

The decade of the 1990s is ushering in a relatively new context for medical decision-making. Until very recently, patients have been expected and usually quite willing to comply with the "Doctor Knows Best" status quo. Traditional paternalistic attitudes are being replaced with shared decision-making between doctor, patient, and oftentimes, family members (Fowler, 1989). Additionally, in the past two decades there has been an increasing emphasis on patient rights (though not responsibilities) and the concept of

autonomy. Autonomy has at its roots principles of self-determination and self governance in all situations (Calman, 1988). A dilemma arises when the patient is old and viewed as incompetent to make autonomous choices regarding care and treatment.

Guidelines for ethical decision-making have been appearing in recent literature (Crabtree & Caron-Parker, 1991; Smith & Weaver, 1987). Smith and Weaver (1987) note that the current healthcare system provides alternatives from which a patient can choose but fails to address issues such as what health policy should be on a global as well as a personal level and fails to acknowledge the ethical dilemmas raised by such policies.

Typical bioethical models focus on patient autonomy as the central element of the paradigm. Crabtree and Caron-Parker (1991) enumerated three models from which the foundation of current ethics derive. First, the medical model assumes that the acutely ill patient can be cured or compensated for any losses incurred due to the illness. Secondly, the contractual model mirrors any other business transaction; the patient is assumed to voluntarily comply with the actions of the health care provider. Thirdly, the humanist model assumes individuals act as rational, free agents, able to choose medical services in their own best interests.

More current research is investigating care and justice considerations used in ethical dilemmas when making medical decisions for self or family versus others (Peter & Gallop, 1994). This research contributes to the knowledge base regarding the reasons behind decisions but does not address whether the decisions would be the same for different aged patients or across age groups. Additionally, the role of gender in decision-making is not addressed.

While much attention is given to ethics, very little to date has related ethical decision-making with possible ageism (Moody, 1992). As technology supersedes our current ethical orientation, it is crucial that the issues of ageism and ethics be studied as a whole, rather than simply two parts. It is important to ensure that medical decision-making is truly based on ethical principles and not on one's own perception of who is entitled to treatment. In light of an aging population, it is critical to make treatment determinations which will be fair and equitable across generations and not favor the young, simply because it is presumed they have not only so much more time, but also more right to live.

Statement of the Problem

The view of aging as a medical infirmity to be cured has significantly reduced utility in the context of an aging population. The reality is that people are living longer, they become ill, and medical decisions will have to be made. A number of individuals faced with these challenges will consult family and friends for input, much as they would for other kinds of major decisions in their lives.

Several studies bear out the importance of this familial interaction. Kapp (1991) found that sharing in the decision-making regarding their care can be an empowering experience for the elderly. The process is also beneficial to their family members, relieving them of the complete responsibility for decisions and providing them valuable input should surrogate decision-making be required in the future. Smith and colleagues (1988) note the trend that many older patients are willing to relinquish their control over health care decisions and even welcome sharing what they perceive to be a tremendous burden with those whom they trust.

Jecker (1990) highlights the role of intimate others in decision-making. While surrogates have traditionally striven to decide issues the way they presume the patient would want, they have not necessarily had access to the history of the person and therefore do not have the knowledge base from which to draw inferences regarding the patient's wishes (Jecker, 1990). The context of the family with its implied longevity of relationship as well as intimacy, is much more useful for making these assumptions than is the impersonal appointment of a surrogate.

A frequent complication of shared decision-making is conflict among family members and a lack of sanctioning of decisions by the elderly themselves. High (1988) studied the preferences and expectations of the elderly prior to the need for any decisional interventions. Interestingly, while a significant number of participants had told at least one other person of their wishes should they become ill, only a few had written any instructions or considered writing any. There is an ethical gap created by a lack of definite instructions which is often filled with assumptions, presumptions, and family conflicts as decisions needing to be made are made during the stress of an illness.

These critical decisions then are often left to family who may or may not have more than a legal tie to the patient and who may or may not have the patient's best interest in mind. Hardwig (1990) proposed that the medical community may be expecting family to sacrifice their own interests in favor of the patient. While it is traditionally assumed that illness leads to vulnerability, in family dynamics, "the patient is not always the weakest member, the member most in need of protection" (Hardwig, 1990, p. 6).

Medical care decisions are increasingly being made using the concept of substituted judgment (High, 1991; Meier, 1992). The central premise of

substituted judgment is that the surrogate will make exactly the same decision in a given circumstance as would the patients themselves. While many generations have made decisions for family members based on their intimate knowledge and day to day experiences, the advent of the Cruzan case (Cruzan v. Director, Mo. Dept. of Health, 1990) has brought under serious debate the right of family members to make such decisions. And, because it is so difficult to predict what others, even in one's own family would want in a given situation, the use of advance directives is becoming increasingly common. By the use of advance directives, family members and medical care providers are given a legalistic solution to what is essentially a moral dilemma (Clark, 1991).

The demands on the family were further explored by Callahan (1988). His treatise ponders what we owe each other in times of crisis and stress, particularly when our own happiness and fulfillment is threatened. He further questions the assumption that care by family is somehow superior or more caring than care by strangers.

Clearly the majority of people in a population which is living longer will experience some type of illness. Many of these people will have a lengthy illness which will require various medical treatment decisions to be made, either by themselves or for them. While the decisions can be made by self or others, and grounded in ethics or emotions, the decisions will be based on some personal criteria of the decision maker. While decisions by medical providers have been extensively researched, personal and family decision-making has often been neglected. This lack of empirical evidence is the foundation of this research study.

Purpose of the Study

The purpose of the study is to determine if age and gender of the patient, as well as level of attachment one has to the patient, affect the outcome of a medical decision made for that particular patient. Additionally, personal characteristics of the decision maker including age, religious beliefs, family composition, and gender were assessed as they relate to the medical decision chosen.

Questions Addressed

Several research questions guided the research effort. These include:

1. Does patient age affect the level of care chosen in the event the patient cannot choose?
2. Does patient gender affect the level of care chosen in the event the patient cannot choose?
3. Does level of attachment to a patient affect the level of care chosen?
4. What qualitative factors are considered in making medical decisions for others?

Theoretical Orientation

Ethical and Moral Dimension

The basis for medical decision-making has been discussed in the literature in terms of bioethical theories and moral development. Horner and Miehl (1991) emphasize that while ethical principles can be used to guide decision-making, the context of an ethical decision does not lend itself to simplistic, black and white answers, even when a decision-making model is used. There is also the moral dimension which is not as amenable to model specification.

The moral dimension is provided for in axiological and deontological theories. Axiological theories have a tendency to imply situational ethics in

that each situation is unique and each individual must make a decision in the context of the situation. It is assumed that acts have an inherent morality and that moral decisions should be based on the act itself (Allmark, 1992).

Deontological theories posit that moral decisions should be made on the basis of duty and are the foundation of official moral codes. From this perspective, acts tend to be universalized and form the basis for the common ethical premise of best interest. Best interest implies only what is best for a person, eliminating any discussion of preferences as would take place using the substituted judgment imperative (Allmark, 1992).

The problem of medical decision-making is best studied within a family sciences framework by asking questions which probe the reasons behind a decision and the types of considerations used to arrive at a decision. Appropriate questions would elucidate the rationale for the decision, which is assumed to be made within the context of multiple environments, including the family, and shaped by values and culture. The family sciences view is superior to other approaches for studying this problem since others tend to separate people from their behaviors, environments, and relationships. Family science does not assume that a person exists within a cultural vacuum with little or no input from external sources. Rather, the whole person is considered in the context of a whole lifetime: values, beliefs, experiences, and environments all inclusive.

Two distinct yet complementary theories are applicable to the problem of ethical, as well as generationally equal medical decision-making: Kohlberg's Theory of Moral Development and Family Developmental Theory.

Kohlberg's Theory of Moral Development

Kohlberg focuses on the development of moral reasoning and decision-making, noting that they develop over time in a stage-like fashion. Each stage is thought to represent a higher level of functioning as a person progresses from concern with consequences to self, to consequences for others, to universal justice norms. Moral reasoning and autonomous decision-making are the central themes of the theory, with emphasis on the reasoning process leading to a decision yielding more information about development than the decision itself (Gielen, 1991).

The concepts underpinning Kohlberg's theory include justice and fairness, obligations, duties and commitments, and standards, rules, and principles (Peter & Gallop, 1994). Kohlberg's model is hierarchical and assumes that a person operates at the highest level obtained, with no movement between levels based on circumstances (Miller, 1984). Kohlberg's theory is impartial, analytical, and based on universal principles.

Kohlberg rejects the notion of biologically timed stages which form the basis for crises and the ensuing tasks necessary to resolve them. Rather, he focuses on processes, stating ". . . adult development is primarily a matter of dropping out of childish modes of thought rather than the formation of new or higher modes of thought," (Kohlberg & Kramer, 1976, p. 577). The childish thought patterns are presumed to be extinguished by late adolescence since little evidence for development occurs after the early 20s (Kohlberg & Kramer, 1976). The theory does assert that moral conceptions and reasoning evolve during childhood as the result of cognitive transformations. Kohlberg saw no evidence for adult cognitive transformations and instead attributed the adult component of development to

". . . a continual process of matching a moral view to one's experience of life in a social world," (Kohlberg & Kramer, 1976, p. 584). Though the developmental processes are fully described in various works, how development takes place is largely left unanswered.

Two perspectives on moral development as the basis for ethical decision-making are prominent in the literature. There is a significant debate between Kohlberg's (1978) concept of a moral development scale and Gilligan's (1982) alternative model. Miller (1984) compared and contrasted the two approaches, concluding Gilligan's female based model had more application for nursing than Kohlberg's male based model. Cooper (1989) further states that the very traits that have traditionally defined "goodness" for women, their care and sensitivity to others, are the very traits that identify them as deficient in moral development when Kohlberg's model is used (p. 11). While these two scholars continue their debates and others continue to critique them, there remains the need for ethical dialogue in medical and nursing schools, but more importantly, in every community. As more people have the opportunity to learn the foundations of ethics and to reflect on personal and familial decisions, there should be less of a need for adjudication of personal, moral choices.

When theories of bioethics and moral development were being developed, decisions regarding the dying patient were made based on an inability to significantly alter outcomes or substantially prolong life. In the context of the advances in medical technology that are taken for granted in the 1990s, it is imperative that society and families bring their focus not on death as a definable, finite, isolated event, but on the process of dying which can be extended for an indefinite period of time. This shift will provide a newer, more accurate context for the medical decisions surrounding the end

of life. Special consideration should be given to patient and family concerns regarding quality of life, quality of the death experience, termination of treatments, and identification of decision makers (Barondess, Kalb, Weil, Cassel, & Ginzberg, 1988). These considerations of the patient in the context of the family are best described from a family developmental theory perspective.

Family Developmental Theory

In order to view medical decision-making from this perspective, it is essential to identify assumptions of the theory and relate them to the decision-making process. Aldous (1978) proposed five basic assumptions that were closely related to earlier assumptions advanced by Hill and Hansen in 1960. These assumptions are:

1. Family behavior is the sum of past experience of family members as incorporated in the present as well as in their goals and expectations for the future.
2. Families develop and change over time in similar and consistent ways.
3. Humans not only imitate actions as they mature and interact with others but also they react to environmental pressures.
4. The family and its members must perform certain time-specific tasks set by themselves and by persons in the broader society.
5. In a social setting, the individual is the basic autonomous unit. (Pp. 57-58).

The necessity of making a medical decision for a family member can easily be related to assumption four, family members have time specific tasks. It can be fairly assumed that as a family member ages and perhaps becomes unable to make decisions, other family members would act as surrogates. Also, the premise that behavior is the sum of past experiences will have a

direct impact on the decision to be made and the resultant outcome. For this problem, previous experience with life support decisions will have an impact on the decision to be made.

The most salient assumption is that humans react to environmental pressures. Certainly in the context of making a medical decision, it can be expected that economic status and other concomitant stressors will influence the decision to be made. These assumptions have provided the variables which have been operationalized and quantified for use in this research project.

Other family developmental concepts pertinent to the project include time, role, and norms. Family developmental theory has been used extensively since the 1950s as the basis for explaining the processes observed in families over time. Indeed, the concept of family time is the focus of the theory and is one point which not only differentiates family development from other perspectives but also enables observation and analysis of the life course (Mattessich & Hill, 1987; Rodgers & White, 1993). Certainly the family's experiences during transitions throughout their history will affect any decisions to be made in the future. It should also be noted that the medical decision is not typically instantaneous but also involves a slice of time for its completion.

The role assumed in the family by the decider and the patient are also germane to the discussion regarding medical decision-making. It is quite possible that the person who has typically been in authority in the family will in fact be the recipient of a surrogate decision. This could initiate a cycle of stress as it violates the prevailing family norms. Other developmental characteristics of the decider which could influence the outcome of a medical decision are the individual's developmental level, level of moral reasoning,

and the family's developmental stage. Each of these is a potential determinant of the decider's maturity and capacity to make such a decision.

Definition of Terms

Specific terms used in the study will be defined as follows.

Ethical dilemma: A dilemma involves the choice between alternatives that appear equally unattractive (Lawrence & Crisham, 1984). An ethical dilemma further involves profound conflicts in one's personal values as the alternatives are considered (Payton, 1989).

Moral Reasoning: "Moral reasoning is used to refer to the cognitive and developmental process of reasoning about moral choice," (Ketefian, 1989, p. 509).

Life support decision: A life support decision is the outcome chosen for a particular patient. The levels of life support are on a continuum and range from supportive and comfort measures only to complete cardiopulmonary resuscitation. These levels are further defined in the instrumentation section.

Advance directive: An advance directive is also referred to as a living will. It is a declaration by the patient outlining his or her preferred treatment in the face of various terminal events. The Patient Self-Determination Act (PSDA) of 1990 requires all agencies which accept federal monies to ascertain upon admission the presence of a patient's living will (High, 1993).

Ageism: Discrimination based on a person's age or perceived age. Ageism typically refers to age based discrimination of the elderly.

Assumptions and Limitations

Several assumptions have been made regarding the study. These include:

1. Subjects will be able to project what they would do in a given situation.

2. Subjects will answer all questions to the best of their capabilities without intentional deceit.

Factors which limit the study include:

1. The use of a convenience sample limits the generalizability of the study results.
2. The relatively small sample size also limits the utility in predicting outcomes in other populations.

Summary

Whether for self or for another, the making of a life support decision will likely confront the majority of Americans. Factors which influence the decision and the decision- making process need to be identified and evaluated. Results of such an assessment have implications for future public policy as medical resources become increasingly scarce. The preponderance of the literature has focused on medical providers decisions related to end of life choices. Targeting the family will provide an additional perspective which to date has not been fully explored.

CHAPTER II

REVIEW OF LITERATURE

Several concepts are germane to the discussion of ethics and medical decision-making. First, a summary of decision-making, not just as an isolated activity, but as a process is presented. Second, the traditional framework of medical decisions by patients, family, and physicians is discussed. Finally, the foundations of ethical principles and how decisions for others are ethically constructed is explored.

Decision-Making

The primary focus of past research on decision-making has been deontic reasoning which involves not only inferring what actions may or should be taken, but also the attendant cognitive functions of probability, utility, and social perspective (Evans, Over & Manktelow, 1993). The process of drawing inferences, like reasoning or decision-making, is itself a high level thought process. Real life reasoning, however, is not easily modeled in laboratory reasoning tasks because people do not tend to restrict themselves to given information; rather, they depend on relevant knowledge they already posses and apply it to the problem at hand. Selecting which knowledge to retrieve and apply is based on the aforementioned cognitive processes of probability, utility, and social perspective. Thus, reasoning in the real world supports decision-making and its aim of goal achievement (Evans, Over & Manktelow, 1993).

In addition to reasoning, decision-making is also characterized by the source of motivation. Weinstein (1993) notes that motivation to act is

derived from the expectation that action can decrease the likelihood or the intensity of harm to self. Motivation research related to health concerns has typically employed one of four models: 1) health belief model (Becker, 1974); 2) subjective expected utility theory (SEU) (Edwards, 1954); 3) protection-motivation theory (Maddux & Rogers, 1983); or 4) theory of reasoned action (Fishbein & Ajzen, 1975). While all of the models have useful components, the theory of reasoned action is most pertinent to current discussions in the family sciences.

Unlike other models, the theory of reasoned action incorporates the component of social influence (Fishbein & Ajzen, 1975). This influence is described as how invested others are in an individual performing a given behavior as well as how deeply the individual is motivated to comply with each of their preferences. Additionally, the consequences from acting or not acting according to the preferences of important others are presumed to be an underlying motivator and contributor to the overall decision-making process (Fishbein & Ajzen, 1975).

Another unique feature of the theory of reasoned action is its focus on behavioral intention rather than observed behavior or behavioral outcome. Family science research relies heavily on processes involved in interpersonal relationships and a focus on intention naturally complements this perspective. Because intentions can vary but lead to the same observable behavior or outcome, how the perspective of the individual decision maker shapes outcome must also be considered.

Billig (1991) states that thinking itself is most simply a process of argument or debate against alternative views. Which view is ultimately chosen is due in large part to the perspective or the lens with which a given situation is viewed.

The adoption of a perspective describes a boundary in what can be perceived (Montgomery, 1994). This differs from a perception which consists of apprehending stimuli from the environment and where the viewing angle of the perceiver can give rise to multiple perspectives. In cognition, perspective is achieved by the adoption of certain roles or by identification with certain persons or interests. Interests are typically the values and beliefs adopted by an individual.

In the adoption of a perspective, people classify the view in terms of ego, we, or other. This classification system becomes especially important when one is confronted with a decision to be made for others. Montgomery (1994) has shown that when people identify the self with some other, they are said to share an inside and outside perspective and that the other is then viewed in a positive manner. Viewing others positively or negatively has potentially grave implications when applied to medical decision-making.

Decision-Making Research

Four decades of behavioral decision-making research has focused on human judgment, especially probability judgment (Frisch & Clemen, 1994). Additional areas of interest subsumed under this topic include the risk perception involved in decision-making and how decisions are made under conditions of certainty versus uncertainty. More currently, emphasis has shifted to processes such as how information is apprehended from the environment, how it is subsequently processed and weighted, and the influence of both personality and environmental perspectives (Tinsley, Holtgrave, Reise, Erdley & Cupp, 1995). The notion of perspective complements the decision-making framework of interpretation, evaluation, and integration of information and ultimately choice of an alternative (Montgomery, 1994).

The context in which decisions occur provides meaning; context is also referred to as the frame for the situation (Mitchell & Beach, 1990). Bierman (1989) notes the necessity of considering all elements when evaluating alternatives and emphasizes that the framing of choices is critical since researcher biases can easily be obscured depending on presentation. This phenomenon, called framing effect, refers to the finding that people's choices can vary as a function of how a situation is described or framed (Frisch & Clemen, 1994). Assuming it is true that framing influences decisional consequences, it can be reasonably argued that a decision could vary as a function of frame (Kahneman & Tversky, 1984).

Kadane (1992) notes that the structure of choices may induce the chooser to frame the choices in a game-like structure. In experiments then, extreme caution must be paid to how subjects' beliefs about the experimenter and the experiment can inadvertently influence subject's behavior.

Rational decision-making in research subjects has been studied extensively using the aforementioned subjective expected utility (SEU) model. This model is derived from utility theory, a mathematical model used to describe people's preferences among gambles. In SEU, rather than employing mathematical formulas to explain decision-making, a person's subjective probabilities for uncertain outcomes are used. While SEU is meant to serve as a normative guide for the individual decision maker, it is not an adequate process model since there is no attention to option generation, consequences, or relevant risks (Frisch & Clemen, 1994).

Further criticism of SEU is offered by Weinstein (1993) who notes that it can only be used to predict the relative likelihood of action and not to predict who will or will not act. A logical corollary to this view is that

knowing which action is most attractive is not sufficient to predict individual behavior.

Evans and colleagues (1993) state that rational decision-making also involves forecasting rather than simply optimizing utility across all possible outcomes. They further critique the notion of classical decision theory or SEU noting that it fails to take into account people's practical reasoning and instead requires them to conform to an abstract mathematical mode. This departure from probability calculus and its normative principle of logic has classically been interpreted as a demonstration of pervasive bias and irrationality. Mitchell and Beach (1990) however, note that most decisions are answered intuitively without reliance on counting and analysis. Because of these inherent problems associated with SEU, several new models for decision-making have been proposed.

New Models for Decision Making

Frisch and Clemen (1994) posit that a good decision has three components based on: 1) relevant consequences of the presented options; 2) an accurate world view where all consequences are considered; and 3) trade-offs are made in some form. This model is somewhat related to the model of decision rule learning proposed by Busemey and Myung (1992). In this model, individuals learn to predict pay-offs by applying a set of learned decision rules and by continuing to fine-tune these rules as they adjust the parameters (or reframe) as necessary.

Montgomery (1994) developed a dominance search model for decision processes in which one alternative dominates the others. The model is highly cognitive and involves the following four steps: 1) screening of alternatives, termed pre-editing, 2) selecting a candidate for the final choice, 3) dominance testing which involves ascertaining the disadvantages of the

promising alternative, and 4) dominance structuring wherein disadvantages are neutralized and advantages are embraced.

Mitchell and Beach (1990) propose it is inappropriate to employ high-powered, precise maximizing models to describe the normal flow of decisions. Instead, they focus on what they refer to as Image theory where decision-making is centered on the future, on goals, and on progress toward goal achievement. Further, they differentiate automatic decision-making from intuition by describing it as a sense of recognition and retrieval of policy from memory rather than an ambiguous feeling. Though commonly regarded as intuition in decision-making, the automatic process actually has an evaluative effect which is so immediate, there are no prior conscious inferences drawn about the situation.

A decision can be conceived as having three distinct phases: 1) the initial situation, 2) the moment of decision, and 3) the situation after the decision (Montgomery, 1994). While previous research has tended to focus strictly on the moment of decision, newer research is discovering that post-decision processes can serve to consolidate the prior decision (Svenson & Benthorn, 1992). Consolidation refers to the factual restructuring that takes place after a decision is made whereby the chosen alternative is widely differentiated from its competitors. This process serves to increase the certainty that the right choice was made, even from among similar alternatives. In this manner, decisions are reinforced and made available for retrieval at a later time if one is confronted with a similar dilemma (Svenson & Benthorn, 1992).

Decision-making has been characterized as a complex process subject to both internal and external influences. A final influence related to medical decision-making is the influence of the family.

Currently, it is estimated that 82.5% of the American population resides within a family structure (U.S. Bureau of the Census, 1990). Living with others and sharing tasks as well as concerns, can have a profound influence on values, beliefs, perspective, and behavior. Lackman & Lanasa (1993) found that decisions which involved a high amount of risk were most often the product of joint decision-making processes in the family. Additionally, the role a family member plays in decision-making was found to vary over time, between families, and between individual decisions. As might be expected, conflict in family decision-making was not typically handled in a rational manner. As the following section demonstrates, the rights of an individual are often discredited or ignored by family members when the topic is medical decision-making.

The Role of Advance Directives in Preserving Individual Rights

In an effort to ensure the rights of individuals, all health care institutions which accept federal funding are now required to ascertain on admission if the patient has a living will, also called an advance directive (AD). The Patient Self Determination Act (PSDA) of 1990 applies not only to hospitals but also to nursing homes, hospices, and home health agencies. In addition to inquiring about the existence of the directive, these agencies are mandated to implement policies regarding recognition of an AD, as well as to educate their staff and the community at large about living wills (High, 1993).

Characteristics of Advance Directives and Their Use

One of the assumptions of the PSDA is that patients will execute a living will if they are given enough information and encouragement (High, 1993). Despite a federal law and community education efforts, the use of advance directives remains limited. In 1989, prior to the PSDA, Zweibel and Cassel (1989) reported only 4-15% of people in the U. S. had a living will and

most of them were older adults. In 1995, that number is only 20%, a minimal increase by even the most generous standards (Herbst, Lynn, Mermann, & Rhymes, 1995).

Though one study showed the elderly were willing to discuss advance directives, they were still infrequently used. More importantly, even when the person had completed one, their personal physician was unaware of its existence (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991). Two preliminary studies of people over age 60 indicate advance directives are not being used, even though the study participants had high levels of familiarity with and understanding of them (High, 1993). An important finding from the same study is that people who attend an instructional meeting and are given assistance with preparation are more likely to complete an advance directive (High, 1993).

As might be expected, there is also experimental evidence which indicates major differences in outcomes dependent upon the way choices are presented. For example, patients are much less likely to opt for a procedure which is presented with an 80% mortality rate than for one in which they are told 20% of all people survive the treatment (Malloy, Wigton, Meeske, & Tape, 1992). These two studies highlight the need for further community education and standardized language in advance directives.

As evidenced by the limited use of advance directives, there are still some very real barriers to their implementation. The completing of an advance directive requires decisional capacity and simulates future hypothetical medical situations (Diamond, Jernigan, Moseley, Messina, & McKeown, 1989; Malloy et al., 1992). The nature of the process forces patients to contemplate the end of their life, an experience which can be unsettling at best.

Zweibel and Cassel (1989) outlined four additional requirements: 1) prioritize qualities of life one values; 2) understand how those qualities might be threatened during illness; 3) understand available treatment options; and, 4) comprehend the implications of choice and refusal of various treatment options (p. 620). These requirements are complex, evoking spiritual and emotional responses more often than intellectual decisions.

Because the response to one's own death is often so emotional, even when advance directives are completed, it is frequently with vague, ambiguous or general preferences rather than specific treatment choices (Lo, 1989). If choices are stated clearly, it is still unrealistic to believe the advance directive can anticipate all future decisions. Lo (1989) has suggested that to be meaningful, the directive requires a series of mutual discussions with patient and physician and perhaps family, rather than a single declaration by the patient.

One tool which is becoming increasingly popular is the values history form. While this is not a legally binding document, it helps the patient and family explore wishes and attitudes regarding life and death and can lead to meaningful dialogue prior to completing the advance directive (Schroeder-Mullen, 1995). Even if uncomfortable, dialogue and completion of the directive may prevent having to make perhaps an even more onerous choice, that of terminating life support (Skegg, 1984).

To help ensure autonomy and not being forced to receive unwanted treatment, options beyond the living will also need to be presented to patients and the public. By definition, the living will specifies a patient's wishes about medical treatment to prolong life, only in cases of terminal illness (less than 6 months to live) or when death is imminent. A step beyond is the durable power of attorney for health care or designation of a proxy. This ensures that

the person the patient chooses will make decisions for them should they become incompetent to do so. A living will may include a provision for a proxy but it is not yet standardized (Schroeder-Mullen, 1995). An additional area which lacks uniformity is people's attitudes to living wills.

Attitudes Regarding Advance Directives

As might be expected, responses to living wills vary widely, and there is no significant predictor of interventional preference. In a study of 405 patients, Emanuel and colleagues found no correlation between age of respondent, health status, education, or any other demographic factor to a chosen intervention (Emanuel et al., 1991). What is consistent is the belief that a living will should be legally binding (Genuis, Genuis, & Chang, 1994; Lo, 1989). One interesting finding is that 41% of respondents who identified themselves as religiously active were opposed to making living wills legally binding (Genuis et al, 1994). No reasons were given for this particular preference and to speculate on them might lead to erroneous conclusions regarding this minority subset. Paradoxically, though 74% of respondents felt directives should be legally binding, only 46% felt hospitals should require executing one on admission (Genuis et al, 1994). The belief that hospitals should not require advance directives (though mandated to inquire about their existence) coupled with their limited use leads to questions about why they are not more prevalent.

Barriers to Use

As previously mentioned, most people, especially the elderly are comfortable deferring medical decisions to their physician. A natural outgrowth of this idea is the belief that the physician will take the initiative in discussing an advance directive if one is needed (Emanuel et al., 1991; High, 1993). Other reasons cited for not preparing a directive include feeling

it is too early to plan, believing the issue is only relevant for people who are older or in poor health, and perceiving barriers to execution such as cost, availability of witnesses or a notary (Emanuel et al., 1991; High, 1993). The most frequently cited reason for not executing a living will is the expectation that others, presumably family and physicians, will handle the issue when the time comes. This attitude reflects a widespread confidence that people can rely on others in crisis situations (High, 1993).

The most important implication for research and public policy is the least cited barrier to use; lack of knowledge or sensitivity to the topic (Emanuel et al., 1991). People are obviously cognizant of the issue yet still find reasons to put off preparing a directive, expecting family to perform as surrogates if necessary.

Role of Families and Surrogates

Surrogates are expected to base their decisions on one of two ethical principles: substituted judgment or best interest. Substituted judgment is assumed to be just that - the judgment the patient would make in the given situation. It is based closely on the known values and preferences of the patient and is considered a mirror of their own decision. Best interest is somewhat more complicated. To act in someone's best interest, data such as prospects for survival, improvement and recovery and the burden that process imposes in terms of dignity, financial cost, and physical pain to the patient all must be considered (Capron, 1994).

The concept of patient's best interest is both delicate and emotionally charged. It is frequently emotionally easier for physicians and families to justify the withholding of treatment because of their belief that the patient would not want it rather than to take personal responsibility for that decision. In judging patient's best interest, surrogates must be compelled to view best

interest from the patient's perspective and not ascribe their own preferences to the patient (Lo, 1989).

Family members are assumed to be appropriate surrogates and to act in the patient's best interest (Lo, 1989; Lo, Rouse, & Dornbrand, 1990). More often than not, a very close family member such as a spouse or adult child is chosen to be the surrogate decision maker. Findings from a study of people with and without directives were virtually identical; fifty-eight percent of respondents with an advance directive chose an adult child as proxy while 61% without a directive made that choice. Figures for the spouse as proxy were 21% and 29% respectively. As might be expected, if participants were married, 84% chose their spouse as proxy indicating confidence that they would know their preferences or act in their best interest (High, 1993).

Scholars disagree on the rights of proxies. Calman (1988) asserts that while relatives do have a right to be involved in patient care, they do not have the right to determine treatment or what is told to the patient. In direct opposition, Lo (1989) believes that families must be allowed to exercise discretion in interpreting patient preferences and best interest. A noted ethicist, Brody, states the right of the family to refuse care for the patient is in fact a delegated authority from the patient to the family so they can exercise the patient's right on their behalf (Brody, 1988).

Research supports that in the absence of direct discussion with the patient, substituted decision-making is not likely to correspond to their preferences (Danis, Southerland, Garrett, Smith, Hielema, Pickard, Egner & Patrick, 1991; Emanuel et al., 1991; Diamond et al., 1989; Zweibel & Cassel, 1989). Diamond and colleagues (1989) found 45% of proxies had prior discussions with patients regarding life sustaining treatment and 70% felt

very sure of their substituted judgment. Unfortunately, there were discrepancies in patient and proxy data 30% of the time (Diamond et al, 1989).

Informal advance direction did not improve the effectiveness of proxies in a study by Zweibel and Cassel (1989). Proxies made decisions opposite to patient preference from 24-50% of the time, depending on the intervention under discussion. Of the pairs who differed on initiation of cardiopulmonary resuscitation (CPR), 70% of the proxies asked for a do not resuscitate (DNR) order while the patients request was to be resuscitated. This finding is collaborated by Danis and colleagues who found family members consistently preferred to have life sustaining treatments withheld from the patient more frequently than the competent patients did for themselves (Danis et al., 1991).

In an Israeli study of adult children and their parents, 52% of proxies claimed they knew the patient's wishes with regard to life support and treatment preference but only 46% subsequently requested that those wishes be followed (Sonnenblick, Friedlander & Steinberg, 1993). In a culture which places less emphasis on autonomy, it is not surprising that only 50% of the adult children believed their competent parent should be involved in the decision-making process, believing that exposure to a grave dilemma might impose an unbearable burden.

As can be inferred from these research findings, quality of life judgments by surrogates can be particularly suspect. Though proxy decisions are often at odds with patient preferences, there does, however, tend to be a high correlation of personal treatment preferences and the choice made for others with congruence rates of 93-95% (Sonnenblick et al., 1993; Zweibel & Cassel, 1989).

The literature indicates family, even with the best of intentions, are not always well informed and consistent surrogates. Adult children and physicians frequently rate the quality of life of an older person lower than the people do themselves, leading to increased frequency of withholding life supporting treatments (Zweibel & Cassel, 1989). Additionally, in some families, there may be conflicts of interest between the proxy and patient or between family members. Conflicts may include being unwilling to listen to others and to recognize one's own bias, not having the patient's best interest at heart, and problems with decision-making, including being too involved to be objective (Lo, 1989). Whether decisions are made by patients, physicians, or proxies, there is ultimately a choice made and natural consequences which follow.

End of Life Decisions

As previously noted, physicians and families commonly base their decisions on previous statements by patients, inferring from these that they are making a substituted judgment or acting in the patient's best interest. In reality, those statements are being interpreted in the revealing light of a specific clinical situation. The specific situation is as much a part of the context of the decision as the values and character traits of the decider. To assume that one can decide in any given situation what a patient would want, based on their past behavior, assumes an unrealistic degree of consistency in the person's life and previous decisions (Lo, 1989). It is preferable to complete a directive in as specific terms as possible and then for it to be followed to guarantee contiguous autonomy.

An example of inconsistent decision-making can be found in a study of elderly outpatients. Though frequently cited as wanting CPR, once the information on CPR survival rates (5-30%) is given to them, the majority

refuse this option (Herbst et al., 1995). Emanuel and colleagues (1991) found no difference in patients' rates of refusal for high tech interventions as compared to simple tube feedings and hydration. Patients made no distinction between ordinary and extraordinary means and none between short term and protracted care, factors that would typically be considered by surrogates acting in the patient's best interest (Emanuel et al., 1991). Full agreement is not reached on the issue of pain medication; nearly 78% of patients want continued pain medication, even if it hastens death, while only 58% of their surrogates would choose this option for them (Emanuel et al., 1991; Sonnenblick et al., 1993).

Estimates of treatment consistency with patient decisions and advance directives range from 33-75% (Danis et al., 1991). Disturbingly, this consistency was less likely to occur when a directive was present in the medical record than when it was absent (Danis et al., 1991). Several factors are involved in the process which can lead to the directive not being followed.

One likely factor previously mentioned is that providers are frequently unaware of the existence of directives. Further, the provider may feel that the initial preference was too restrictive to allow for care which is believed to be appropriate at the time. Alternatively, the treatment chosen may, in the provider's view, afford little benefit to the patient. Finally, families may contradict the advance directive (Danis et al., 1991).

Since incompetent patients are four times more likely to receive treatment inconsistent with their wishes (Danis et al, 1991), it would appear that appointing a trusted person as proxy would be a better way to ensure continued autonomy. Without this, legal battles often ensue which cast the courts into the role of making patient care decisions, one for which they are grossly unprepared.

Legal Implications

Three court cases have helped to shape current medico-legal thinking on the subject of life support and advance directives. With a brief nod to patient rights, the New Jersey State Supreme Court found that it is a common law right to refuse any medical treatment. The court did require, however, what it termed "trustworthy" evidence that a patient would refuse treatment and that the burden of a continued life outweighs its benefits (In re Conroy, 1985; Zucker & Annarino, 1986). Prior to the State Supreme Court hearing the case, a guardian had won the right to remove a feeding tube in trial court which was reversed on appeal. The appellate court implied that removal of the feeding tube would be active euthanasia or killing the patient rather than simply letting her die (Nevins, 1988).

The major implication in this case is the court's offer of how to decide what a patient would wish if not expressly stated in a written directive. The method calls for combining patient intent with burden, defined as painful suffering which outweighs any physical, emotional or intellectual satisfaction the patient might derive from life. The method further rejects any judgments made on the basis of age per se, personal worth, social utility, or value to others (Nevins, 1986). The court's suggested method of deciding treatment was to assign an ombudsman and two physicians unrelated to the case to gain consensus. Then, presumably, the physician actually attending the patient could be persuaded to follow the proposed plan.

In a similar case, the New York Court of Appeals authorized nasogastric feedings for Mary O'Connor though she had previously stated she " . . . would never want any sort of intervention, any sort of life support systems . . ." to prolong her life (Lo, 1989, p. 215). The reason the court gave for its decision is that she had never specifically discussed feeding tubes and

that there was not clear and convincing evidence that she would reject them (In the matter of Mary O'Connor, 1988). With characteristic omniscience, the court further dismissed her previous statements as an immediate reaction to unsettling experiences, though she had worked in an emergency room, taken care of two relatives who died from cancer, and been previously hospitalized herself (Lo, 1989). An important finding related to families is that the court rejected surrogate decisions based on what the patients would have wanted or in their best interest. The court did hold, however, that written directives were more trustworthy (Lo, 1989).

Legal scholars tend to agree that competent patients have the right to refuse medical care, including those treatments which would sustain life (Capron, 1994). In the case of Nancy Cruzan, the Missouri court severely limited the right of families to make the same refusal on behalf of an incompetent patient without the most rigid of formalities, such as a living will (Lo et al., 1990). While on one hand the court seemed to favor directives, it expressed skepticism about them on the other, stating "It is definitionally impossible for a person to make an informed decision either to consent or to refuse under hypothetical circumstances" (Lo et al., 1989, p. 1229). In the matter of the state's interest, the court was more clear, expressing concern for the prolongation of an individual patient's life and in the sanctity of life itself (Capron, 1994).

The U.S. Supreme Court heard the case and affirmed the Missouri ruling. The appellate court ruling suggested that the interests of third parties may override those of a patient in a persistent vegetative state. The Supreme Court held that a state does not violate the due process clause when it refuses to allow foregoing of a patient's life support, in the absence of clear and

convincing evidence that the patient had expressed such a wish while still competent (Cruzan v. Director, Mo. Dept. of Health, 1990).

It is important to note that the courts made these rulings based on clinical information which was anywhere from months to years old, preferring to cross examine witnesses rather than to examine the patient. In contrast, a physician who neglects patient examination is rendered definitionally incompetent (Lo et al., 1990). Without the ability to examine a patient and make a clinical determination, the courts would seem better suited to choosing and disciplining surrogates rather than making decisions regarding patient care.

Role of the Physician

The role of the physician in life support appears to be uncertain as society demands more patient autonomy and the courts erode the role of clinical decision-making (Mason & Smith, 1983). Kennedy (1984) states that the doctor has no greater expertise than the layman in dealing with ethical issues. While they may not have more expertise, it can be argued they have greater experience since they deal with life and death on a daily basis.

The physician's role in the patient's death has traditionally been to provide comfort, information, and to carry out the patient's wishes. In order for those wishes to be clearly elucidated, it is essential that the physician take the initiative in discussions of advance directives, ensuring they are informed and realistic (Lo, 1989). The ideal time for such a dialogue is the first office visit, during the history taking. Once the topic is broached, further explorations can take place as the patients preferences for feedings, antibiotics, blood transfusions and CPR are defined (Herbst et al., 1995). Indeed, it is incumbent upon the physician to hold these discussions while patients are still competent, to urge them to choose a surrogate and indicate precisely how

much discretion the surrogate will be allowed (Lo, 1989; Lo et al., 1990). If physicians do not take the lead in promoting advance directives, they are in essence abdicating their duty to the patient and leaving a window of opportunity for challenge by hospitals, families, and the courts.

Foundations of Ethics and Moral Reasoning

Ethical dilemmas in the United States are increasingly initiated in the context of medical decisions and often, at the end of life. These medical ethical problems are frequently resolved using autonomy as the primary focus (Meier, 1992). The roots of autonomy rest in the text of the Colonies' Declaration of Independence from Great Britain: "We hold these truths to be self-evident, that all men are created equal, that they are endowed by their creator with certain inalienable rights, that among these are Life, Liberty, and the Pursuit of Happiness," (Declaration of Independence, 1776).

The impact of this statement is to promulgate equality of all persons and the right of all persons to pursue their own notions of good. In subsequent years, the Bill of Rights offered further basic protections of personal liberties and entrenched autonomy as a national value.

Ethics

Ethics, morals, and values are customarily used interchangeably in everyday speech. In fact, their underlying definitions share some common themes but clear, distinct, differentiation is important in understanding the dynamics inherent in end- of -life medical decisions.

Omery (1989) characterizes ethics as both an art and a science. Ethics is art in that it involves an intuitive sense of correspondence that can be gained only by the lived experience. Ethics is science as it weighs, assesses, analyzes, and studies relationships using empiric evidence (Omery, 1989).

Ethics is often mistakenly conceptualized as simply the personal values learned in childhood (Ryden et al., 1989). More accurately, ethics is described as a branch of philosophy that deals with questions of human behavior (Horner & Miehl, 1991). Morality, moral problems, and moral judgments are then properly subsumed under the larger notion of ethics.

Fowler (1989) also characterizes ethics as a division of philosophy but adds that ethics can properly be a branch of theology as well. Philosophically studying morality, moral problems, and moral judgments is further categorized as: 1) the descriptive study of morality or descriptive ethics; 2) meta-ethical study of moral judgments; and 3) the normative study of moral problems or normative ethics.

The descriptive study of morality implies the factual description of moral beliefs or behaviors often cited in sociological, historical, anthropological, and psychological research. This scientific approach to morality provides the framework for the philosophical study of morality. Descriptive morality accounts for real-life situations but makes no judgments on the morality of the behavior or belief (Fowler, 1989).

While descriptive ethics explains what is, meta ethics is concerned with theories about ethics. These theoretical issues of meaning and justification typically remain the domain of professional ethicists and are not germane to the present context of individuals choosing end-of-life decisions for others.

Determinations of right and wrong, good and evil, and what ideally should be are the province of normative ethics. Ethical principles and the moral rules that assist individuals in determining what ought to be done, who they should be, or what they should seek constitute ethical norms and are therefore examined in this category.

Two basic types of norms emerge from normative ethics: norms of value and norms of obligation. Norms of value can be considered in terms of moral values (such as what is good or evil) and non-moral values (such as what we are to be or to cherish). Norms of obligation are at the core of ethical decision-making and are concerned with what is right or wrong action. Obligation or duty is independent of the concept of good because the consequences of actions do not always determine the rightness or wrongness of the action itself (Czerwinski, 1990). Classic ethical considerations of autonomy, beneficence, non-maleficence, and justice are derived from theories of moral obligation (Fowler, 1989).

Ethical Principles

A brief review of the principles underlying ethics will facilitate understanding more complex notions of ethical dilemmas and moral reasoning. These concepts include autonomy, beneficence, paternalism, non-maleficence, and justice.

Autonomy derives from respect for human life itself and the right to determine one's life course within the limits of avoiding harm to others. Early in this century, Justice Benjamin Cardoza wrote, "Every human being of adult years and sound mind has a right to determine what shall be done to his own body," (Schloendorff v. Society of New York Hospitals, 1914). In this decision, however, Justice Cardoza made no provision for minors or the mentally incompetent, two categories of persons who receive much of the attention surrounding modern care dilemmas. Some more recent court decisions have also upheld the primacy of an individual's values and beliefs in medical decision-making, particularly in terminating life support (Miles et al., 1989; Nevins, 1988).

Beneficence implies a duty to others by doing good for them or helping them avoid harm. Best interest directly derives from this principle (Meier, 1992). Paternalism can be conceptualized as best interest carried to an extreme, when the best interest of an individual is determined by the judgment of others (Fowler, 1989). In recent years, hospitals and physicians have increasingly wanted to impose treatments over the refusal of an informed patient or family (Tulsky & Lo, 1992). Sanctity of all life is the most frequently cited argument of paternalism which seeks to avert what the decision maker deems is a bad decision on the part of another. Through the lens of the decision maker, their own decision supersedes all others, both quantitatively and qualitatively. Paternalism, then, is the direct antithesis of autonomy.

Non-maleficence is the most stringent principle in health care ethics and quite often overrides the consideration of other principles. Non-maleficence is quite simply to do no harm and has its roots in the Hippocratic oath taken by all physicians (Fowler, 1989).

The final common ethical principle is justice which implies fairness or in the case of healthcare, equitable access to treatment. Distributive justice underlies the spreading of benefits and burdens among individuals and groups in society (Meier, 1992). These principles, autonomy, beneficence, non-maleficence, and justice are frequently cited as the basis on which most ethical dilemmas are resolved.

Moral Problems and Ethical Dilemmas

Jameton (1987) proposed that ethics is fundamentally concerned with three types of moral problems: 1) moral uncertainty or the nature of the problem, including what rules apply; 2) moral dilemma or the conflict of principles which would enjoin different courses of action; and 3) moral

distress or knowing what is right action but being prevented in some way from carrying it out. Most life support decisions are the result of a moral dilemma though in some cases, family disagreement and moral distress may play a role. Tulsky and Lo (1992) have noted many dilemmas in clinical ethics are the result of disagreements between the wishes of patients or surrogates and the physician. Rarely is moral uncertainty a problem in medical decision-making because the nature of the problem is usually described with substantial empiric data.

When moral claims conflict with one another, an ethical dilemma arises. The dilemma most often presents as a difficult problem with little capability of a satisfactory solution. It can also present as a choice or situation involving equally unsatisfactory or unattractive alternatives (Horner & Miehl, 1991). Omery (1989) notes that there is an inherent complexity and subtlety in ethical dilemmas which further adds to the difficulty in their resolution.

When seeking to solve an ethical dilemma, most people rely on personal moral values, an internal code of right and wrong, ought and ought not. These values tend to be hierarchically organized whether or not an individual is cognizant of this fact. Because of this hierarchy, the criteria for judging some things becomes more desirable than others. And, because values are subjectively acquired, they are easily reinforced or manipulated by the family, the social environment, or one's professional group (Omery, 1989).

Rather than relying on personal morality, Fowler (1989) has suggested two models for ethical decision-making. The first is the casuistic model which is case centered and highly focused on immersion in the specific details of a situation. The model is designed to assist in cases where broader

principles such as respect for autonomy do not appear to be adequately sensitive. The strength of this model is its practicality and acknowledgment of specific circumstances. Directly derived from this strength is the primary limitation where the circumstances are manipulated to fit the decision while general rules and principles may be ignored.

More commonly used is the analytic model, also called the deductivist model due to its reliance on deductive application of principles and rules (Fowler, 1989). This model focuses on principles and rules which underlie analysis and judgment rather than on broad ethical theories. A strength, therefore, would be the potential for equality in practical decision-making. An important limitation, however, is the rejection of context or circumstances which makes each situation unique.

Tulsky and Lo (1992) assert that more than simple ethical reasoning is required in resolving ethical disputes. They suggest that discussion and negotiation are critical to the process of resolution. Further, they state that emotional and interpersonal factors generally are at least as important, if not more so, than logical arguments. The focus on interpersonal factors can lead to a more communitarian ethic.

Meier (1992) argues that individuals are never truly autonomous or separate from their primary moral relationships with other people and their communities; this focus underlies a communitarian ethic. Communitarianism promotes attention to the common good of family or society as a consideration in solving dilemmas. Widespread use of this ethic is not currently practiced in the United States where autonomy still reigns as the overarching, governing principle in medical-ethical disputes.

Characteristics of Moral Reasoning

Moral reasoning is a necessary component of ethical decision-making. And, in order for moral reasoning to take place, cognitive processes must be intact (Duckett et al, 1992). Ryden and associates (1989) contend that the ability to reconsider and perhaps revise one's position is an important indicator of principled reasoning and in fact, is equated with the highest levels of moral development. The assumption that moral development is invariant and hierarchical, however, has been criticized by Kurtines and Grief (1979). These authors argue that moral development is a highly individualized process which does not necessarily manifest in a step-wise pattern. Rest (1979) concurs, stating that development of moral reasoning does not progress just because people grow older.

Ketefian (1981) states that the development of logic is necessary for and sets the limits of moral development. Further, most individuals appear to be higher in the logical development stage than in the moral domain. Interestingly, greater than 50% of late adolescents and adults are capable of full formal reasoning but only 10% display principled moral reasoning (Ketefian, 1981). Ryden and colleagues (1989) add that both outcome and process must be appropriate in principled action.

Though moral reasoning is predicated on cognition, Nisbett and Wilson (1977) found that individuals are often not aware of their own mental processes, particularly those which lead to judgments. In their study, participants were asked to articulate the processes which led to a particular judgment. Quite often, they were unable to do so. The implications for ethical dilemma resolution are clear in this example; many judgments are made using considerations of feelings, values, and principles which are not or cannot be verbalized.

Berger, Seversen, and Chvatal (1991) studied nurses and their dilemma solving patterns. When respondents ranked the resources they used, personal values were the most frequently cited. Consultations with nursing colleagues, friends, administrators and finally, family, followed in successive order. Again, moral reasoning appears as a highly personal and individualized process.

Moral reasoning is directly linked to moral behavior or action (Rest, 1979). In later work, Rest (1986) proposed a four component process model which leads to a moral decision or moral action. The model begins with recognition that a moral problem exists with rights, duties, values, or principles in conflict. This stage is termed moral sensitivity. Moral reasoning occurs when conflicts are weighed and a course of action is determined. Moral commitment gives priority to moral values over other potentially competing values. At this stage, one commits to doing what is perceived to be morally right. The final stage is the actual implementation of the moral decision which requires ego strength and good communication skills (Rest, 1986). Duckett (1992) characterized the four component model as encompassing the concept of caring which some refer to as ethical sensitivity.

Variable Effects on Ethical Decision Making

Gender is often considered as a variable in tests of moral reasoning. After extensive review, Walker (1984) found that men and women do not score differently on the Kohlberg interview and are both capable of higher levels of moral reasoning. Omery (1989) describes Kohlberg's stage three, mutual morality, as doing what is expected of people in similar roles. The majority of the population, irrespective of gender, has a propensity for stage arrest at this point. Research by Hoyer and associates (1991) found that autonomous thinking, clear decision-making, and responsible action are

typically masculine ascribed traits which are often viewed as undesirable in women. This perception, however, does not translate into gender proscribed ethical decisions.

The effects of education on ethical reasoning are less clear. Keller (1985) found education in general and previous ethics education in particular were not significant factors in one's level of moral reasoning. Later research (Duckett et al., 1992) on nursing students found that the level of moral reasoning tends to increase when people engage in formal education or specific types of intervention programs. There was no longitudinal data, however, to determine if effects persist over time or if people revert to previous decision-making modes.

Further research on nursing students (Crisham, 1981; Davis, 1981; Ketefian, 1981; & Munhall, 1980) failed to reveal any significant demographic variable effects on scores of ethical responsibilities. Age, socioeconomic status, religion or religiosity, and ethnicity all appear to be unrelated to moral reasoning or the resolution of ethical dilemmas. These findings provide level ground for all persons making ethical decisions and suggest that other variables account for differences in decisional outcomes.

Summary

The literature describes several models for decision making which have traditionally been based on mathematics and reasoned action. Current models view decision making as a process rather than a point in time.

Advance directive research has focused on attitudes of medical personnel or patients. Several studies have highlighted the inconsistencies in choices a patient would make for self, versus the choice a family member would make for that patient. People do appear to choose the same life support options for themselves that they would choose for others.

Ethics and moral reasoning have been assumed to be the basis for difficult decisions such as those at the end of life. Research does not support this commonly held belief. Rather, when confronted with an ethical dilemma, a person will generally resort to core values inculcated in childhood which rarely coincide with the foundations of either ethics or moral reasoning.

CHAPTER III

METHODS

This study was designed to explore the nature of the relationship between an individual's perception of old age and the resultant life support they would choose for someone they classify as elderly. Life support decisions are typically emotionally charged with many underlying values, beliefs, and past experiences contributing to the final decision. Little is known about how life support choice is impacted by the advanced age of the person chosen for.

Previous research has focused on medical practitioners life support choices or patients' choices for themselves. This study focused on individuals' choices for family, as well as for people they do not know. Additionally, qualitative data regarding the rationale for the choice of age, gender, and life support was collected in an effort to determine if ethical constructs underlie these critical decisions.

Research Methodology

Isaac & Michael (1995) state the purpose of correlational research as investigation of how differences in one factor relate to differences in one or more other factors. These differences are statistically described using correlational coefficients.

Certain attributes further define correlational research. First, it is useful when variables are complex or not subject to controlled manipulation. Second, it realistically assesses variable interrelationships. Third, it describes

the amount or degree of relationship rather than the simple presence or absence of an experimental effect (Isaac & Michael, 1995).

Though widely used, especially in the social sciences, the method is not without several limitations. These include:

1. Inability to determine cause and effect relationships;
2. Less rigor in the approach due to less control over independent variables;
3. Tendency to identify spurious relational patterns; identified patterns may be arbitrary;
4. Outcome data may defy meaningful interpretation due to indiscriminate use of miscellaneous data (Isaac & Michael, 1995).

These concerns can largely be addressed by grounding the research effort in formal theory and taking note of relationships from previously completed rigorous studies.

Descriptive research components are often incorporated into other research designs. Isaac and Michael (1995) state the purpose of descriptive research as, "To describe systematically the facts and characteristics of a given population or area of interest, factually and accurately," (p. 50). Descriptive research is characterized by the literal nature of the approach. There is no effort to examine relationships, test hypotheses, predict, or explain the implications of the data. Situations and events are only described; there is no further embellishment made or inference drawn from the data (Isaac & Michael, 1995). Miller (1991) calls this approach observational, adding that all sciences, behavioral and traditional analytic, have observation as a root method.

The present study employed a combination of the two preceding methods, correlational and descriptive. The study further sought to determine the relationship between definitions of elderly and middle aged, and resultant life support decisions for others. Additionally, the relationship between gender and life support decision was explored. Finally, factors which led to the life support decision were ascertained. Relationships between these factors and level of life support chosen were described and examined in terms of patterns, trends, and common themes. The factors included age, gender and religious preference of the decider and age and gender of the person for whom the choice was made. Other factors were discovered by asking qualitative questions regarding rationale for choices made. Statistical correlations were completed for this data as well.

Sample

The non-probability sample consisted of people 18 years old and older and was drawn from the following areas: 1) city workers in a large metropolitan area in the midwest; 2) residents of a retirement village; and 3) a land-grand university in the midwest (full respondent demographics are presented in Table 3, Appendix C). Participation was strictly voluntary and there were no inducements or punishments for participation or non-participation. The subjects remain anonymous unless they were willing to be contacted for follow up interview, which they indicated on the survey form. In both cases, all information was kept strictly confidential and the surveys were destroyed at the completion of the project.

The sample was purposive in order to obtain sufficient numbers from various age groups. The sample was also one of convenience in order to maximize numbers of respondents using available research funds. True

random sampling was not practical for this project because of the time and expense involved to gain a random sample of people 18 years old and older.

The average age of the respondent was 38 years. A clear majority (72%) were female and over one half (54%) were married. Eighty-six percent were white with some college education(50%) and were typically employed in a business or technical occupation (61%).

The data were collected by the researcher at the aforementioned sites. Prior to data collection, appropriate Institutional Review Board approvals were obtained from all involved institutions and agencies.

Research Questions

Overall questions relevant to ethical dilemmas relate to the influence of age, gender, and degree of attachment to level of life support chosen for others. Qualitative factors which lead to specific life support outcomes were also of interest.

Specific questions which guided the research effort were:

1. Does level of life support chosen decrease as age increases?
2. Is there a difference in life support chosen according to gender of person chosen for?
3. Does level of life support chosen increase as level of attachment to another increases?

Stated in the research or null form, the questions become:

1. There is no difference in level of life support chosen based on age of person chosen for; age has no influence on level of chosen life support.
2. There is no difference in level of life support chosen based on gender of person chosen for; gender has no effect on level of chosen life support.

3. There is no difference in level of life support chosen based on level of attachment to the person chosen for; level of attachment has no effect on chosen life support.

Underlying the null form of the questions is the assumption that deciders will base all outcomes on a personal moral code or ethical paradigm which does not vary according to situation or context.

Variables

Correlational studies do not necessarily distinguish between the dependent and independent variables. In this study, however, a distinction was made in some cases to assist in explanation of the study results.

Independent variables which were measured include basic demographic data (age, gender, marital status, family composition, education, occupation and religious preference). Age and education were conceived as interval level data. The remainder were nominal level.

Conventionalizing or answering questions in the way one perceives they should be answered is a significant problem in social sciences research (Edmonds, 1967). In order to determine if subjects were following what they perceive is a socially desirable pattern of responses, a social desirability scale was developed for use in conjunction with the survey. Score on the social desirability scale is an independent variable measured at the interval level. The scale uses a Likert-type format which transforms essentially nominal or ordinal data into interval level data. A full explanation of the social desirability scale is included in the instrument section.

Two response variables, age and gender of the vignette subject were treated as independent variables. Age was measured intervally and gender nominally.

The dependent variable was the level of life support chosen. Again, the data is essentially ordinal since the scale begins with basic treatment and becomes more complex. Since life support is conceived as a continuum, however, the data can potentially be treated intervally by assigning successive numbers to more complex treatments.

Model

The variable relationships can be conceptualized in a model (see Appendix A). The model is a two dimensional representation of a three dimensional concept. Though there is a line representing time across the top of the model, and the process which brings the participant to the study is longitudinal, the actual completion of the survey appears at one point in time, making this study cross-sectional.

Demographic data (age, religious preference, family composition, gender, occupation, and education) and developmental characteristics (role, individual development level, family developmental stage) influence characteristics of the decider. These characteristics include previous experience with life support decisions, level of attachment to person decided for, and conformance to socially desirable answers. An assumption was made that adults participating in the study have experience with everyday decision-making and have the cognitive capability to make various choices, including those related to life support.

The decider's characteristics may either positively or negatively impact the decision to be made. Age and gender of the person decided for also potentially impact the decision. For the purposes of this study, prognosis and living will preparation were held constant. No person described in a vignette had a living will. Further, all the vignettes had the same wording to decrease ambiguity and minimize respondents' interjections into the details of the

vignettes. For example, coma can result from a stroke, a car wreck, or a viral illness. Though the net result is the same, the context may influence how one chooses a life support option. Controlling this potential source of variance should allow for minimal focus on detail and maximum focus on what internal factors influence decisions. A final influence on the decision would be prevailing family and social norms. The decision itself was one of four levels of life support: 1) full CPR, 2) CPR and drugs, no intubation, 3) drugs only, no CPR, and 4) nutrition/fluids/pain medicine only.

Instrument

The full text of the instrument appears in Appendix B. The instrument was conceived in three parts: demographics, a social desirability scale, and the seven medical decision-making vignettes.

The demographic questions were designed to obtain routine background information on the respondent and, to provide information on family characteristics such as composition, developmental stage, and roles. Though previous literature has not highlighted demographic variables as influences on ethical dilemma resolution, the current study of lay persons in a family context did elicit different relationships.

An issue as emotionally charged as choosing life support for others has a high potential for the confounding effect of social desirability. A brief scale to determine the relationship of social desirability to life support decisions was developed by the researcher.

The scale was developed using social desirability as an overall construct. In the case of life support decision-making, three concepts or dimensions were employed to define social desirability: religiosity, attachment, and knowledge/previous experience with life support decisions.

The concepts were further operationalized using four questions for each of the three categories.

Concepts in the Social Desirability Scale

Religiosity was used since it is widely believed that people who consider themselves religious are more inclined to preserve life at all costs and will choose high levels of life support. Attachment is more nebulous since healthy attachment allows for others to maintain their own boundaries and autonomy. In this scale, however, people with a high level of attachment are predicted to choose increased complexity of life support measures such as full CPR, ventilators, antibiotics, and surgeries.

Knowledge or previous experience with life support decision-making is thought to relate to lower conformance with social desirability in this area. People scoring high on this dimension (but overall low in social desirability) will be more likely to choose options other than full or complex life support; those options might include pain medications and nutrition only.

It is believed that people with high social desirability scores will also have a high preference for full or nearly all inclusive life support measures such as ventilators, chest compressions, antibiotics, surgeries, nutrition and fluids, and pain medication. Those scoring lower will more likely choose comfort measures and fluids and nutrition only, at least in most cases.

Thus, the scales for social desirability and life support correlate high scores with high scores and low scores with low scores. Following is a diagram of the two scales.

Life Support Preference Scale	LO_____	HI
	Comfort	Full
CPR		
Social Desirability Scale	LO_____	HI

Social Desirability Scale

To score essentially ordinal data in an interval fashion, a Likert type scale was used for the three dimensions. Scores for each item will range from 1-7 on a scale as follows:

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

The scores could also easily use the words agree/disagree rather than yes/no.

A total score for the 12 questions (four on each of three dimensions) could range from 12-84. For each dimension, a score could range from 4-28.

Items and Rationale of Social Desirability

The questionnaire was formatted with the item below so that participants can easily see the relationship between the question and their response. Subjects were asked to circle the response which most reflects their feelings about the question. Example:

1. I consider myself to be religious.

1 2 3 4 5 6 7

Table of Social Desirability Questions

1. I consider myself to be religious.
2. All human life is sacred.
3. There is life after death.
4.* Money is always a consideration, even when a life is at stake.
5. Family is the most important part of my life.
6.* People always have the right to make their own decisions.
7. I always ask my family for advice when making decisions.

8.* Career decisions always come first for me.

9. Death on TV is realistic.

10.* I have made life support decisions for others.

11. Living wills are only a guide. Family must decide life support if a member becomes incompetent.

12.* I have completed or plan to complete a living will (advanced directive).

*Indicates the item is reflected. A reflected score is scored in reverse with a 1 equaling a 7, a 2 equaling a 6 etc. Reflected items were used to determine if participants were marking all answers the same versus actually reading and answering each question individually.

Questions 1-4 relate to religiosity. The concept was operationalized by asking questions related to values and directly asking if the respondents consider themselves to be religious. Questions 5-8 relate to attachment. These questions investigated involvement with family in order to operationalize the concept. Questions 9-12 relate to knowledge/previous experience with life support decisions. This concept was operationalized by asking questions which probe experience and the respondents conception of the reality of death.

Social desirability when making life support decisions could potentially have two distinct directions. First, people may have wanted to be perceived as good and loving, supportive of life in any circumstance. It was believed that these people would score high on dimensions related to religiosity and attachment and low on the dimension related to knowledge/previous experience with life support.

Conversely, there are those who would put quality of life above quantity of life, who have perhaps had some experience in making life

support decisions, and who would respect the wishes of others, even when not congruent with their own. These people would tend to score high on the knowledge dimension and could score anywhere on the attachment and religiosity dimensions. It was recognized that to be highly attached, one does not have to be highly intrusive or disrespectful of relationship boundaries. This group of people were presumed less likely to be concerned with appearances and social desirability and would overall still score lower on the complete scale.

Vignettes

The vignettes were researcher developed to reflect a consistent medical diagnosis and prognosis across all situations. Respondents were asked four questions at the end of each vignette: What is the age of the person? Is the person male or female? What level of life support would you choose? What factors did you consider when making this decision. The language of the life support options was adapted from Malloy, Wigton, Meeske, and Tape (1992). Their research has shown that the descriptive language can significantly influence the level of life support chosen. The language presented was clinically accurate and realistic but not clinically obscure or negative. Seven forms of the instrument were offered to reduce presentation bias.

Reliability and Validity of the Instrument

Both the social desirability scale and the vignettes used in the current study were researcher developed. The vignettes were assessed for face validity by three physicians and three registered nurses. The social desirability scale was extensively analyzed and the results are reported in Appendix B.

Analysis of the Social Desirability Scale

The intent of the social desirability scale was to determine if certain constructs such as knowledge of life support decision, attachment, or religiosity affect the life support options one chooses for another. Spearman rank correlations were completed for each subscale as well as the complete scale. Results are displayed in Table 1, Appendix C. Each subscale and the complete scale were compared with each of the seven different scenarios.

For the complete social desirability scale, the more socially desirable the responses, the more likely full CPR was chosen by the respondent ($p \leq .001$, see Table 6). On the religiosity subscale, the higher the score on religiosity, the more likely full CPR was chosen ($p \leq .05$, see Table 1). The knowledge subscale suggests that the greater one's previous knowledge of, or experience with life support choices, the more likely one is to choose nutrition only over full CPR ($p \leq .05$). No significant relationship was found between attachment and life support options chosen.

The total score on the social desirability scale is strongly related to each subscale. The subscales, however, are independent of each other (See Table 2, Appendix C).

Reliability coefficients were computed for the social desirability scale and for each subscale. The Cronbach's alpha for the total scale was .2403: for the religiosity subscale, .4733: for the attachment subscale, .1857, and for the knowledge subscale, .2427. The values for the attachment and knowledge subscales suggest that perhaps there is more than one construct being measured by the subscale.

Various permutations of the social desirability scale were calculated in an effort to obtain a more reliable measure. For example, on the religiosity subscale, inclusion of items 1, 2, and 3 only resulted in a Cronbach's alpha of

.6315. Also, item 8 on the attachment scale, when reflected, is somewhat lower than when normally scored (.340 vs. .346). However, when item 8 reflected is calculated into the overall scale, the alpha is .321. This result indicates that while item 8 (concerning career importance) does not belong in the attachment subscale, it may measure social desirability in the broader sense.

Item 10 (having made a life support choice in the past) was most highly correlated with item 12 (having made a living will for self), with $r = .23$ at $p \leq .004$. This is consistent with the results for the knowledge subscale which suggest that items 10 and 12 alone are the most reliable indicator of social desirability in this area (Cronbach's alpha = .3734). Further testing and refinement of the scale and subscales is indicated by all of these results.

Procedure

The researcher obtained access to the sites previously described. On the specified day, the researcher visited the sites to administer the instrument to volunteer participants. At that time, instructions were given to the participants and questions were answered. All participants received a survey booklet and a separate sheet of life support definitions to assist them in responding to the vignettes. There were no research assistants so that the information provided to all groups was the same. Participants may have elected to identify themselves on the instrument if they were willing to be contacted for a follow-up interview. All interviews were conducted by the researcher and the information obtained is held strictly confidential.

Data Analysis

Correlational studies were completed to determine variable interrelationships. Because most of the relationships addressed included data

which was ordinal and interval, Spearman Rank correlations were used for the majority of the analysis.

For some of the data which included nominal and ordinal variables, the ordinal were converted to nominal and contingency coefficients were obtained. This resulted in a more conservative estimate than either the Spearman or Pearson methods and decreased the likelihood of identifying potentially spurious relationships. The relationship of qualitative factors and life support choices was analyzed using a one way ANOVA with post-hoc analysis employing the Scheffe test.

Summary

A correlational study was designed to determine if there is a relationship between certain factors (e.g. age, gender) and life support choice. A purposive, non-randomized sample was obtained to represent three stages of the adult life-span: early adulthood, mid-life, and later adulthood. A researcher developed questionnaire was employed, with subsequent statistical analysis performed on 151 responses.

CHAPTER IV

ETHICAL DILEMMA RESOLUTION: AGEISM AS A FACTOR IN MEDICAL DECISION MAKING

MANUSCRIPT FOR PUBLICATION

JOURNAL TITLE: JOURNAL OF ETHICS, LAW AND AGING

Abstract

This study, grounded in theories of moral development, was designed to determine the effect of age on life support choices for others. Additionally, gender and attachment were considered as factors which might affect the choice made for another. The sample consisted of 151 respondents, representing the entire adult life span from early adulthood through later adulthood. The researcher developed instrument included demographic information, a social desirability scale, and seven vignettes in which the respondent chose the age, gender and life support option. The results suggest that the least aggressive support options (i.e. nutrition and fluids only) are chosen for the elderly. Gender and attachment had no effect on the level of care chosen. Factors cited for the lack of support include a long life and that the decider was certain of the individual's wishes. To ensure that choices are made ethically and free of ageist bias, open dialogue must be encouraged in families.

ETHICAL DILEMMA RESOLUTION: AGEISM AS A FACTOR IN MEDICAL DECISION MAKING

Recent advances in medical technology have contributed to the growth in the elderly population or age wave (Dychtwald and Flower, 1990). Dychtwald and Flower (1990) state that the fastest growing segment of the U.S. population is the over 65 age group, with the fastest growing portion of that cohort being the over 85 year olds. Each day, thousands of senior citizens check in to America's hospitals, some electively and some emergently. When they do, they are transported into a world of futuristic life sustaining technology which engenders previously non-existent ethical dilemmas. Treatments and procedures that were mere blueprints only five years ago are today saving and prolonging lives and are being eclipsed by second and third generations of their line. Employing more procedures, better equipment, and faster cures seems to be the way all patients are treated, from those in utero to centenarians drawing their last breaths.

Unfortunately, our societal code of ethics, medico-legal precedents and our own familial interactions have fallen short of keeping pace with bioscience. For example, there is the physical capability to undertake coronary bypass surgery on an 85 year old patient but the moral rightness of using resources in this way, and the assessment of the impact on the patient and family have been sorely neglected. In a race to promote life at all costs, society has failed miserably to ascertain what those costs might be.

Paradigm for Decision Making

The view of aging as a medical infirmity to be cured has significantly reduced utility in the context of an aging population. The reality is that people are living longer, they become ill, and medical decisions will have to be made. A number of individuals faced with these challenges will consult

family and friends for input, much as they would for other kinds of major decisions in their lives.

The decade of the 1990s is ushering in a relatively new context for medical decision-making. Until very recently, patients have been expected and usually quite willing to comply with the "Doctor Knows Best" status quo. Traditional paternalistic attitudes are being replaced with shared decision-making between doctor, patient, and oftentimes, family members (Fowler, 1989). Additionally, in the past two decades there has been an increasing emphasis on patient rights and the concept of autonomy. Autonomy has at its roots principles of self-determination and self governance in all situations (Calman, 1988). A dilemma arises when the patient is old and viewed as incompetent to make autonomous choices regarding care and treatment.

Typical bioethical models focus on patient autonomy as the central element of the paradigm. Crabtree and Caron-Parker (1991) enumerated three models from which the foundation of current ethics derives. First, the medical model assumes that the acutely ill patient can be cured or compensated for any losses incurred due to the illness. Secondly, the contractual model mirrors any other business transaction; the patient is assumed to voluntarily comply with the actions of the health care provider. Thirdly, the humanist model assumes individuals act as rational, free agents, able to choose medical services in their own best interests.

Current research is investigating care and justice considerations used in ethical dilemmas when making medical decisions for self or family versus others (Peter & Gallop, 1994). This research contributes to the knowledge base regarding the reasons behind decisions but does not address whether the decisions would be the same for different aged patients or across age groups. Additionally, the role of gender in decision-making is not addressed.

While much attention is given to ethics, very little to date has related ethical decision-making with possible ageism (Moody, 1992). As technology supersedes our current ethical orientation, it is crucial that the issues of ageism and ethics be studied as a whole, rather than simply two parts. It is important to ensure that medical decision-making is truly based on ethical principles and not on one's own perception of who is entitled to treatment. In light of an aging population, it is critical to make treatment determinations which will be fair and equitable across generations and not favor the young, simply because it is presumed they have not only so much more time, but also more right to live.

Clearly the majority of people in a population which is living longer will experience some type of illness. Many of these people will have a lengthy illness which will require various medical treatment decisions to be made, either by themselves or for them. While the decisions can be made by self or others, and grounded in ethics or emotions, the decisions will be based on some personal criteria of the decision maker. While decisions by medical providers have been extensively researched, personal and family decision-making has often been neglected. Additionally, factors which form the foundation of these medical decisions remain virtually unexplored. This lack of empirical evidence is the foundation of this research study.

Purpose of the Study

The purpose of the study is to determine if age and gender of the patient, as well as level of attachment one has to the patient affect the outcome of a medical decision made for that particular patient. Additionally, personal characteristics of the decision maker including age, religious beliefs, family composition, and gender will be assessed as they relate to the medical decision chosen.

Theoretical Orientation

Ethical and Moral Dimension

The basis for medical decision-making has been discussed in the literature in terms of bioethical theories and moral development. Horner and Miehl (1991) emphasize that while ethical principles can be used to guide decision-making, the context of an ethical decision does not lend itself to simplistic, black and white answers, even when a decision-making model is used. There is also the moral dimension which is not as amenable to model specification.

The problem of medical decision-making is best studied within a family science framework by asking questions which probe the reasons behind a decision and the types of considerations used to arrive at a decision. Appropriate questions would elucidate the rationale for the decision, which is assumed to be made within the context of multiple environments, including the family, and shaped by values and culture. The family science view is superior to other approaches for studying this problem since others tend to separate people from their behaviors, environments, and relationships. Family science does not assume that a person exists within a cultural vacuum with little or no input from external sources. Rather, the entire person is considered in the context of a whole lifetime; values, beliefs, experiences, and environments all inclusive.

Two distinct yet complimentary theories are applicable to the problem of ethical, generationally equal medical decision-making: Kohlberg's Theory of Moral Development and Family Developmental Theory.

Kohlberg's Theory of Moral Development

Kohlberg focuses on the development of moral reasoning and decision-making, noting that they develop over time in a stage-like fashion.

Each stage is thought to represent a higher level of functioning as a person progresses from concern with consequences to self, to consequences for others, to universal justice norms. Moral reasoning and autonomous decision-making are the central themes of the theory, with emphasis on the reasoning process leading to a decision yielding more information about development than the decision itself (Gielen, 1991).

Two perspectives of moral development as the basis for ethical decision-making are prominent in the literature. There is a significant debate between Kohlberg's (1978) concept of a moral development scale and Gilligan's (1982) alternative model. Miller (1984) compared and contrasted the two approaches, concluding Gilligan's female based model had more application for the helping professions than Kohlberg's male based model. Cooper (1989) further states that the very traits that have traditionally defined "goodness" for women, their care and sensitivity to others, are the very traits that identify them as deficient in moral development when Kohlberg's model is used (p. 11). While these two scholars continue their debates and others continue to critique them, there remains the need for ethical dialogue in medical and nursing schools, but more importantly, in every community. As more people have the opportunity to learn the foundations of ethics and to reflect on personal and familial decisions, there should be less of a need for adjudication of personal, moral choices.

Family Developmental Theory

In order to view medical decision-making from this perspective, it is essential to identify some assumptions of the theory and relate them to the decision-making process. The necessity of making a medical decision for a family member can easily be related to the assumption that family members have tasks, which are often time specific. It can be fairly assumed that as a

family member ages and perhaps becomes unable to make decisions, other family members would act as surrogates. Also, the premise that behavior is the sum of past experiences will have a direct impact on the decision to be made and the resultant outcome. For this problem, previous experience with life support decisions will have an impact on the decision to be made.

The most salient assumption is that humans react to environmental pressures. Certainly in the context of making a medical decision, it can be expected that economic status and other concomitant stressors will influence the decision to be made. These assumptions have provided the variables which have been operationalized and quantified for use in this research project.

Other family developmental concepts pertinent to the project include time, role, and norms. Family developmental theory has been used extensively since the 1950s as the basis for explaining the processes observed in families over time. Indeed, the concept of family time is the focus of the theory and is one point which not only differentiates family development from other perspectives but also enables observation and analysis of the life course (Mattessich & Hill, 1987; Rodgers & White, 1993). Certainly the family's experiences during transitions throughout their history will affect any decisions to be made in the future. It should also be noted that the medical decision is not typically instantaneous but also involves a slice of time for its completion.

The role assumed in the family by the decider and the patient are also germane to the discussion regarding medical decision-making. It is quite possible that the person who has typically been in authority in the family will in fact be the recipient of a surrogate decision. This could initiate a cycle of stress as it violates the prevailing family norms. Other developmental

family member ages and perhaps becomes unable to make decisions, other family members would act as surrogates. Also, the premise that behavior is the sum of past experiences will have a direct impact on the decision to be made and the resultant outcome. For this problem, previous experience with life support decisions will have an impact on the decision to be made.

The most salient assumption is that humans react to environmental pressures. Certainly in the context of making a medical decision, it can be expected that economic status and other concomitant stressors will influence the decision to be made. These assumptions have provided the variables which have been operationalized and quantified for use in this research project.

Other family developmental concepts pertinent to the project include time, role, and norms. Family developmental theory has been used extensively since the 1950s as the basis for explaining the processes observed in families over time. Indeed, the concept of family time is the focus of the theory and is one point which not only differentiates family development from other perspectives but also enables observation and analysis of the life course (Mattessich & Hill, 1987; Rodgers & White, 1993). Certainly the family's experiences during transitions throughout their history will affect any decisions to be made in the future. It should also be noted that the medical decision is not typically instantaneous but also involves a slice of time for its completion.

The role assumed in the family by the decider and the patient are also germane to the discussion regarding medical decision-making. It is quite possible that the person who has typically been in authority in the family will in fact be the recipient of a surrogate decision. This could initiate a cycle of stress as it violates the prevailing family norms. Other developmental

Evans and colleagues (1993) state that rational decision-making also involves forecasting rather than simply optimizing utility across all possible outcomes. They further critique the notion of classical decision theory or SEU noting that it fails to take into account people's practical reasoning and instead requires them to conform to an abstract mathematical mode. This departure from probability calculus and its normative principle of logic has classically been interpreted as a demonstration of pervasive bias and irrationality. Mitchell and Beach (1990) however, note that most decisions are answered intuitively without reliance on counting and analysis.

A decision can be conceived as having three distinct phases: 1) the initial situation, 2) the moment of decision, and 3) the situation after the decision (Montgomery, 1994). While previous research has tended to focus strictly on the moment of decision, newer research is discovering that post-decision processes can serve to consolidate the prior decision (Svenson & Benthorn, 1992). Consolidation refers to the factual restructuring that takes place after a decision is made whereby the chosen alternative is widely differentiated from its competitors. This process serves to increase the certainty that the right choice was made, even from among similar alternatives. In this manner, decisions are reinforced and made available for retrieval at a later time if one is confronted with a similar dilemma (Svenson & Benthorn, 1992).

Certain variables have been presumed to affect dilemma resolution. Gender is often considered as a variable in tests of moral reasoning. After extensive review, Walker (1984) found that men and women do not score differently on the Kohlberg interview and are both capable of higher levels of moral reasoning. Omery (1989) describes Kohlberg's stage three, mutual morality, as doing what is expected of people in similar roles. The majority of

the population, irrespective of gender, has a propensity for stage arrest at this point. Research by Hoyer and associates (1991) found that autonomous thinking, clear decision-making, and responsible action are typically masculine ascribed traits which are often viewed as undesirable in women. This perception, however, does not translate into gender proscribed ethical decisions.

The effects of education on ethical reasoning are less clear. Keller (1985) found education in general and previous ethics education in particular were not significant factors in one's level of moral reasoning. Later research (Duckett et al., 1992) on nursing students found that the level of moral reasoning tends to increase when people engage in formal education or specific types of intervention programs. There was no longitudinal data, however, to determine if effects persist over time or if people revert to previous decision-making modes.

Further research on nursing students (Crisham, 1981; Davis, 1981; Ketefian, 1981; & Munhall, 1980) failed to reveal any significant demographic variable effects on scores of ethical responsibilities. Age, socioeconomic status, religion or religiosity, and ethnicity all appear to be unrelated to moral reasoning or the resolution of ethical dilemmas. These findings provide level ground for all persons making ethical decisions and suggest that other variables account for differences in decisional outcomes. One significant variable is the family structure and the processes among family members.

Currently, it is estimated that 82.5% of the American population resides within a family structure (U.S. Bureau of the Census, 1990). Living with others and sharing tasks as well as concerns, can have a profound influence on values, beliefs, perspective, and behavior. Lackman & Lanasa (1993) found that decisions which involved a high amount of risk were most

often the product of joint decision-making processes in the family. Additionally, the role a family member plays in decision-making was found to vary over time, between families, and between individual decisions. As might be expected, conflict in family decision-making was not typically handled in a rational manner and, the rights of an individual are often discredited or ignored by family members when the topic is medical decision-making.

Research supports that in the absence of direct discussion with the patient, substituted decision-making is not likely to correspond to their preferences (Danis, Southerland, Garrett, Smith, Hielema, Pickard, Egner & Patrick, 1991; Emanuel et al., 1991; Diamond et al., 1989; Zweibel & Cassel, 1989). Diamond and colleagues (1989) found 45% of proxies had prior discussions with patients regarding life sustaining treatment and 70% felt very sure of their substituted judgment. Unfortunately, there were discrepancies in patient and proxy data 30% of the time (Diamond et al, 1989).

Informal advance direction did not improve the effectiveness of proxies in a study by Zweibel and Cassel (1989). Proxies made decisions opposite to patient preference from 24-50% of the time, depending on the intervention under discussion. Of the pairs who differed on initiation of cardiopulmonary resuscitation (CPR), 70% of the proxies asked for a do not resuscitate (DNR) order while the patients request was to be resuscitated. This finding is collaborated by Danis and colleagues who found family members consistently preferred to have life sustaining treatments withheld from the patient more frequently than the competent patients did for themselves (Danis et al., 1991).

In an Israeli study of adult children and their parents, 52% of proxies claimed they knew the patient's wishes with regard to life support and

treatment preference but only 46% subsequently requested that those wishes be followed (Sonnenblick, Friedlander & Steinberg, 1993). In a culture which places less emphasis on autonomy, it is not surprising that only 50% of the adult children believed their competent parent should be involved in the decision-making process, believing that exposure to a grave dilemma might impose an unbearable burden.

As can be inferred from these research findings, quality of life judgments by surrogates can be particularly suspect. Though proxy decisions are often at odds with patient preferences, there does, however, tend to be a high correlation of personal treatment preferences and the choice made for others with congruence rates of 93-95% (Sonnenblick et al., 1993; Zweibel & Cassel, 1989).

Methods

Previous research has focused on medical practitioners life support choices or patients' choices for themselves. This study focused on individuals' choices for family, as well as for people they do not know. Additionally, qualitative data regarding the rationale for the choice of age, gender, and life support was collected in an effort to determine if ethical constructs underlie these critical decisions.

The present study employed a combination of two methods, correlational and descriptive. The study further sought to determine the relationship between definitions of elderly and middle aged, and resultant life support decisions for others. Additionally, the relationship between gender and life support decision was explored. Finally, factors which led to the life support decision were ascertained. Relationships between these factors and level of life support chosen were described and examined in terms of patterns, trends, and common themes. The factors included age, gender and religious

preference of the decider and age and gender of the person for whom the choice was made. Other factors were discovered by asking open ended questions regarding rationale for choices made. Statistical correlations were completed for this data as well.

Sample

The non-probability sample consisted of people 18 years old and older and was drawn from the following areas: 1) city workers in a large metropolitan area in the midwest; 2) residents of a retirement village; and 3) students attending a land-grand university in the midwest. Participation was strictly voluntary and there were no inducements or punishments for participation or non-participation. The subjects remain anonymous unless they were willing to be contacted for follow up interview, which they indicated on the survey form. In both cases, all information was kept strictly confidential and the surveys were destroyed at the completion of the project.

The sample was purposive in order to obtain sufficient numbers from various age groups. The sample was also one of convenience in order to maximize numbers of respondents using available research funds. True random sampling was not practical for this project because of the time and expense involved to gain a random sample of people 18 years old and older.

The average age of the respondent was 38 years. A clear majority (72%) were female and over one half (54%) were married. Eighty-six percent were white with some college education (50%) and were typically employed in a business or technical occupation (61%). Characteristics of the respondents are shown in Table 3.

The data were collected by the researcher at the aforementioned sites. Prior to data collection, appropriate Institutional Review Board approvals were obtained from all involved institutions and agencies.

Insert Table 3 about here

Research Questions

Overall questions relevant to ethical dilemmas relate to the influence of age, gender, and degree of attachment to level of life support chosen for others. Qualitative factors which lead to specific life support outcomes were also of interest.

Specific questions which guided the research effort were:

1. Does level of life support chosen decrease as age increases?
2. Does gender influence the choice one makes for another?
3. Is more aggressive life support chosen as level of attachment to another increases?

Variables

Independent variables which were measured include basic demographic data (i.e. age, gender, marital status, family composition, education, occupation and religious preference). Age and education were conceived as interval level data. The remainder were nominal level.

Conventionalizing or answering questions in the way one perceives they should be answered is a significant problem in social sciences research (Edmonds, 1967). In order to determine if subjects were following what they perceive is a socially desirable pattern of responses, a social desirability scale was developed for use in conjunction with the survey. Score on the social desirability scale is an independent variable measured at the interval level. The scale uses a Likert-type format which transforms essentially nominal or ordinal data into interval level data.

Two response variables, age and gender of the vignette subject were treated as independent variables. Age was measured intervally and gender nominally.

The dependent variable was the level of life support chosen. Again, the data is essentially ordinal since the scale begins with basic treatment and becomes more complex. Since life support is conceived as a continuum, however, the data can potentially be treated intervally by assigning successive numbers to more complex treatments.

Demographic data (i.e. age, religious preference, family composition, gender, occupation, and education) and developmental characteristics (role, individual development level, family developmental stage) influence characteristics of the decider. These characteristics include previous experience with life support decisions, level of attachment to person decided for, and conformance to socially desirable answers. An assumption was made that adults participating in the study have experience with everyday decision-making and have the cognitive capability to make various choices, including those related to life support.

The decider's characteristics may either positively or negatively impact the decision to be made. Age and gender of the person decided for also potentially impact the decision. For the purposes of this study, prognosis and living will preparation were held constant. No person described in a vignette had a living will. Further, all the vignettes had the same wording to decrease ambiguity and minimize respondents' interjections into the details of the vignettes. For example, coma can result from a stroke, a car wreck, or a viral illness. Though the net result is the same, the context may influence how one chooses a life support option. Controlling this potential source of variance should allow for minimal focus on detail and maximum focus on

what internal factors influence decisions. A final influence on the decision would be prevailing family and social norms. The decision itself was one of four levels of life support: 1) full CPR, 2) CPR and drugs, no intubation, 3) drugs only, no CPR, and 4) nutrition/fluids/pain medicine only.

Instrument

The full text of the instrument is available from the authors. The instrument was conceived in three parts: demographics, a social desirability scale, and the seven medical decision-making vignettes.

The demographic questions were designed to obtain routine background information on the respondent and, to provide information on family characteristics such as composition, developmental stage, and roles. Though previous literature has not highlighted demographic variables as influences on ethical dilemma resolution, the current study of lay persons in a family context did elicit different relationships.

An issue as emotionally charged as choosing life support for others has a high potential for the confounding effect of social desirability. A brief scale to determine the relationship of social desirability to life support decisions was developed by the researcher.

The scale was developed using social desirability as an overall construct. In the case of life support decision-making, three concepts or dimensions were employed to define social desirability: religiosity, attachment, and knowledge/previous experience with life support decisions. The concepts were further operationalized using four questions for each of the three categories.

Vignettes

The vignettes were researcher developed to reflect a consistent medical diagnosis and prognosis across all situations. Respondents were asked four

questions at the end of each vignette: What is the age of the person? Is the person male or female? What level of life support would you choose? What factors did you consider when making this decision. The language of the life support options was adapted from Malloy, Wigton, Meeske, and Tape (1992). Their research has shown that the descriptive language can significantly influence the level of life support chosen. The language presented was clinically accurate and realistic but not clinically obscure or negative. Seven forms of the instrument were offered to reduce presentation bias.

Reliability and Validity of the Instrument

Both the social desirability scale and the vignettes used in the current study were researcher developed. The vignettes were assessed for face validity by three physicians and three registered nurses.

Reliability coefficients were computed for the social desirability scale and for each subscale. The Cronbach's alpha for the total scale was .2403: for the religiosity subscale, .4733: for the attachment subscale, .1857, and for the knowledge subscale, .2427. The values for the attachment and knowledge subscales suggest that perhaps there is more than one construct being measured by the subscale. Further testing and refinement of the scale and subscales is indicated by these results.

Procedure

The researcher obtained access to the sites previously described. On the specified day, the researcher visited the sites to administer the instrument to volunteer participants. At that time, instructions were given to the participants and questions were answered. All participants received a survey booklet and a separate sheet of life support definitions to assist them in responding to the vignettes. The researcher conducted all sessions, therefore the information provided to all groups was the same. Participants may have

elected to identify themselves on the instrument if they were willing to be contacted for a follow-up interview. All interviews were conducted by the researcher and the information obtained is held strictly confidential.

Data Analysis

Correlational studies were completed to determine variable interrelationships. Because most of the relationships addressed included data which were ordinal and interval, Spearman Rank correlations were used for the majority of the analysis.

For some of the data which included nominal and ordinal variables, the ordinal were converted to nominal and contingency coefficients were obtained. This resulted in a more conservative estimate than either the Spearman or Pearson methods and decreased the likelihood of identifying potentially spurious relationships. The relationship of qualitative factors and life support choices was analyzed using a one way ANOVA with post-hoc analysis employing the Scheffe test.

Results

Respondents were presented with seven different situations in which the age of the patient varied. The instructions asked the respondent to specify the age of the person in each situation, with the supplied information indicating only that the person was a child, middle-aged, or elderly.

In situation one, the older the spouse, the more likely they were to receive nutrition only, versus a more vigorous life support alternative. Using a Spearman Rank correlation (because life support data are ordinal while age is interval/ratio), the results are significant with a p value $\leq .01$. This result indicates a strong correlation with age of spouse (M=43.27) and life support choice (see Table 4).

Insert Table 4 about here

Situation two concerned the age of one's child. There was no significant correlation in the age of the child (M=15.04) with any given life support choice. This is the only situation in which full CPR was selected more than nutrition only. Most respondents chose full CPR, regardless of the age of the child. Qualitative comments from the respondents indicated a high value placed on the life of any child, no matter what his or her age.

Situation three described the scenario with an elderly parent. Older parents did not receive full CPR but were given nutrition only as their life support. This result was significant at $p \leq .01$, indicating a strong correlation between the age of the parent (M=72.68) and the nutrition option.

Situation four concerned an elderly neighbor. The mean reported age for this elderly person was somewhat higher (M=75.29) than for the elderly parent. There was a strong correlation ($p \leq .005$) with the age of the neighbor and the chosen life support, with older neighbors receiving nutrition only.

Situation five described a middle-aged co-worker (M=43.93). The results of correlation analysis of age and life support option were not significant at the .05 level for this scenario.

In situation six, the described person was middle-aged, in a hospital, unknown to the respondent. There was no demonstrated relationship between life support option and age (M=49.14) in this case. The age of this middle-aged person, however, is significantly older than the age of the middle-aged co-worker ($t = 46.3$, $p \leq .001$). As in situations three and four, the closer the relationship, the younger the person was chosen to be. Likewise,

persons with whom the respondent were more distant were assumed to be older.

In situation seven, the respondent was asked to choose a life support option for him or herself. Consistent with the other significant results, the older the respondent was in the scenario (M=43.38), the more likely they were to choose nutrition only as a life support choice ($p \leq .001$).

In summary, in most applications, patient age does affect the level of care chosen with older ages being given the least aggressive of the life support options, while a child is usually provided the most aggressive of the supportive measures. There was no demonstrated relationship with any of the life support options and the condition of middle-age.

Respondents were also asked to identify a gender for each of the people in the seven scenarios. In all seven scenarios, gender was not found to be a significant factor ($p \leq .05$) in the chosen life support, using contingency coefficients or Pearson's r. In situation three, however, the elderly female parents were more likely to receive full CPR ($p \leq .05$) than the elderly male parents when a Spearman correlation was employed. Though interesting, this does not change the fact that the elderly parent of either gender was more likely to be given nutrition only and the more conservative estimates found no significant relationship for gender.

Prior to data collection, attachment was thought to correlate highly with the level of life support one would choose for another, with closer relationships resulting in more complex or heroic life support measures. Though no statistically significant relationship was found in the choice of life support for others based on attachment ($p \leq .05$), certain qualitative factors regarding personal feelings emerged as significant in relation to choices.

In addition to qualitative comments, five other factors were analyzed; these included age, gender, religious preference, education level, and respondent's occupation. Spearman correlation coefficients were computed for age, education level, and occupation in relation to each of the seven scenarios. Gender and religious preference were analyzed employing contingency coefficients.

Age of the respondent was statistically significant across all seven scenarios (see Table 5). The older the respondent, the more likely he or she was to choose nutrition only for every situation ($p \leq .05$), including for the child. Younger respondents were more likely to choose full CPR for everyone.

Insert Table 5 about here

Level of education was significant in only two of the seven scenarios: options for self and for one's co-worker. Higher education is related to choosing nutrition only for self and a middle-aged co-worker ($p \leq .05$) but is not related to any other groups, including the unknown person who is also described as middle-aged.

Respondent occupation was found to be significant in only one scenario, that of the middle-aged co-worker (Spearman correlation = .2281, N=150, $p \leq .002$). However, further analysis using age as a co-variate found no relationship between occupation and life support choices.

Religious preference of the respondent had no relationship to life support options chosen in any of the scenarios. Likewise, gender of the respondent was not related to his or her decisions regarding life support for others.

Qualitative Factors

In all, each of 151 respondents was asked to make a life support choice for each of seven different scenarios, for a total of 1057 responses. Additionally, they were asked to list factors which shaped their particular decision in each case. From this large pool of potential responses, only 15 different reasons (including none or blank) emerged as the basis for the life support choice (see Table 6).

Insert Table 6 about here

For each of the seven scenarios, a one way ANOVA was computed, and post-hoc analysis was performed using the Scheffe test. For each of the seven situations listed below, the results were significant ($p \leq .05$).

In situation one (spouse), people who chose factors 2, 9, 10, and 13 (no quality of life, same as self, patient's guessed preference, physician statements) tended to choose nutrition only, whereas those reporting factors 3, 4, and 11 (no chance to live yet, personal feelings, chance of miracles) chose full life support for their spouse.

For situation two (child) the same factors (3, 4, 11) were listed as the basis of a full CPR choice, while 2 and 13 were stated as the basis of the nutrition only option. As previously reported, this scenario was the only one where most respondents chose full life support over the other options.

Situation three describes the elderly parent. Again, factors indicating personal feelings and potential for contribution were linked to full CPR, while long life, no quality of life, and the parent's guessed preference were related to providing only nutrition.

The situation regarding one's elderly neighbor (four) also divided respondents. Full CPR was chosen by those who had moral or philosophical grounds, as well as hope for a miracle. Nutrition only was chosen by those who thought the neighbor had lived a long life and had no potential quality of life.

The co-worker was given nutrition only by those who felt he or she had no potential for quality of life, listed money as a decisional factor, and believed they knew what the co-worker would want. Conversely, those who hoped for a miracle or stated moral grounds for their choice provided their co-worker with full CPR.

Fewer factors were cited when making decisions for an unknown person (situation six). The pattern of choice, however, was consistent as in previous scenarios. Morality/philosophy and the chance for a miracle were cited as reasons for full CPR. Nutrition only was chosen by those who believed the person had no potential quality of life.

Decisions for self (situation seven) were consistent with decisions for others. Full CPR was chosen by those who felt they had not had a chance to live yet, who had religious grounds, or who hoped for a miracle. Nutrition only was chosen by those who felt there was no potential for quality of life and who did not want to be a burden to their families. Interestingly, religious teaching was significant only as a factor in decisions for self but not for others.

For the majority of the responses, there was a presumption that the wishes of the patient were clearly known to the decider. This logically assumes that families are having conversations about end of life issues and personal preferences. Unfortunately, neither the current scholarship nor anecdotal reports support this view. More commonly, family members tend to bicker among themselves about life support options, with each member

claiming to know what the patient wants. Sadly, this most often takes place in a time of great personal strain on the entire family and the life support choice becomes the stage where feelings of guilt and shame, as well as issues of control are acted out.

The other qualitative factor which is somewhat suspect states that the person has no potential for quality of life. This suggests a sweeping over-simplification of what constitutes life quality as well as measures each individual life by the same collective yardstick.

While one family or family member may believe that a person in coma who cannot respond has no potential quality of life, another family may delight in sitting at the bedside, sharing stories, and touching their loved one, thus, having the quality of their own lives enhanced. Because a person may not be sitting up talking and taking nourishment does not preclude that they are contributing to the family in a very real and dynamic way. If one can be moved simply by looking at a museum painting, how much more can be gained by gazing at a loved one who is a part of one's own self?

In conclusion, certain factors appear to be related to specific life support choices. Factors expressing hope, personal feelings, morality and potential contribution were related to full CPR. Perceived lack of quality of life, assumption of the patient's preferences and belief in the physician's stated prognosis were related to less aggressive life support (nutrition only).

Discussion

Decisions regarding life support for self or others are complex and often made when emotions and tensions are running high. The decision can be made by default as when there is no advance directive or, left to family who can often do no more than report what they think the patient would want. As this study suggests, decisions to provide nutrition only to the elderly are

often made based on the premise that they have lived a good, long life. This decision may or may not be consistent with the elderly person's desires.

The literature indicates family, even with the best of intentions, are not always well informed and consistent surrogates. Adult children and physicians frequently rate the quality of life of an older person lower than the people do themselves, leading to increased frequency of withholding life supporting treatments (Zweibel & Cassel, 1989). Additionally, in some families, there may be conflicts of interest between the proxy and patient or between family members. Conflicts may include being unwilling to listen to others and to recognize one's own bias, not having the patient's best interest at heart, and problems with decision-making, including being too involved to be objective (Lo, 1989). These conflicts may be less disturbing to the family if open, honest, communication has preceded the end of life decision.

References

Calman, K. C. (1988). Ethical implications of terminal care. In M. Freeman, (Ed.), Medicine, ethics and the law. London: Stevens & Sons.

Cooper, M. C. (1989). Gilligan's different voice: A perspective for nursing. Journal of Professional Nursing, 5(1), 10-16.

Crabtree, J. L. & Caron-Parker, L. M. (1991). Long-term care of the aged: Ethical dilemmas and solutions. The American Journal of Occupational Therapy, 45(7), 607-612.

Crisham, P. (1981). Measuring moral judgment in nursing dilemmas. Nursing Research, 30, 104-110.

Danis, M., Southerland, L., Garrett, J., Smith, J., Hielema, F., Pickard, C., Egner, D., & Patrick, D. (1991). A prospective study of advance directives for life-sustaining care. The New England Journal of Medicine, 324(13), 882-888.

Davis, A. J. (1981). Ethical dilemmas in nursing: A survey. Western Journal of Nursing Research, 3, 397-407.

Diamond, E., Jernigan, J., Moseley, R., Messina, V. & McKeown, R. (1989). Decision-making ability and advance directive preferences in nursing home patients and proxies. The Gerontologist, 29(5), 622-626.

Duckett, L., Rowan-Boyer, M., Ryden, M. B., Crisham, P., Savik, K., & Rest, J. R. (1992). Challenging misperceptions about nurses' moral reasoning. Nursing Research 41(6), 324-331.

Dychtwald, K. & Flower, J. (1990). Age wave. New York: Bantam.

Edmonds, V. H. (1967). Marital conventionalization: Definition and measurement. Journal of Marriage and the Family, 29(4), 681-688.

Emanuel, L., Barry, M., Stoeckle, J., Ettelson, L. & Emanuel, E. (1991). Advance directives for medical care: A case for greater use. The New England Journal of Medicine, 324(13), 889-895.

Evans, J., Over, D., & Manktelow, K. (1993). Reasoning, decision making and rationality. Cognition, 49, 165-187.

Fowler, M. (1989). Ethical decision making in clinical practice. Nursing Clinics of North America, 24(4), 955-965.

Frisch, D. & Clemen, R. (1994). Beyond expected utility: Rethinking behavioral decision research. Psychological Bulletin, 116(1), 46-54.

Gielen, U. (1991). Kohlberg's moral development theory. In L. Kuhlmerker with U. Gielen & R. L. Hayes (Eds.), The Kohlberg legacy for the helping professions, (pp. 18-38). Birmingham, AL: R. E. P. Books.

Gilligan, C. (1982). In a different voice. Cambridge, MA: Harvard University Press.

Horner, J., & Miehl, J. L. (1991). The deontological decision-making model as a bioethical tool. Association of Operating Room Nurses Journal, 54(2), 208-218.

Hoyer, P. J., Booth, D., Spelman, M. R. & Richardson, C. E. (1991). Clinical cheating and moral development. Nursing Outlook, 39(4), 170-173.

Keller, M. (1985). Nurses' responses to moral dilemmas. Doctoral dissertation, University of South Carolina. Dissertation Abstracts International, 46, 1870B.

Ketefian, S. (1981). Critical thinking, educational preparation and development of moral judgment among a selected group of practicing nurses. Nursing Research, 30, 98-103.

Kohlberg, L. (1978). The cognitive approach to moral education. In P. Scharf (Ed.), Readings in moral education (pp. 36-51). Minneapolis, MN: Winston Press.

Lackman, C. & Lanasa, J. M. (1993). Family decision-making theory: An overview and assessment. Psychology and Marketing, 10(2), 81-93.

Lo. B. (1989). Caring for incompetent patients: Is there a physician on the case? Law, Medicine & Health Care, 17(3), 214-220.

Malloy, T., Wigton, R., Meeske, J., & Tape, T., (1992). The influence of treatment descriptions on advance medical directive decisions. Journal of the American Geriatrics Society, 40, 1255-1260.

Mattessich, P. & Hill, R. (1987). Life cycle and family development. In M. Sussman and S. Steinmetz (Eds.), Handbook of marriage and the family, (pp. 437-469). New York: Plenum.

Miller, L. H. (1984). Alternative approaches to measuring nursing: Gilligan's and Kohlberg's moral development scales. Rehabilitation Nursing, Sept.-Oct., 22-26.

Mitchell, T. R. & Beach, L. R. (1990). ". . . Do I love thee? Let me count . . ." Toward an understanding of intuitive and automatic decision making. Organizational Behavior and Human Decision Processes, 47, 1-20.

Montgomery, H. (1994). Towards a perspective theory of decision making and judgment. Acta Psychologica 87, 155-178.

Moody, H. R. (1992). Ethics in an aging society. Baltimore, MD: The Johns Hopkins University Press.

Munhall, P. (1980). Moral reasoning level of nursing students and faculty in a baccalaureate nursing program. Image, 12, 57-61.

Omery, A. (1989). Values, moral reasoning, and ethics. Nursing Clinics of North America, 24(2), 499-500.

Peter, E. & Gallop, R. (1994). The ethic of care: A comparison of nursing and medical students. Image, 26(1), 47-51.

Rodgers, R. & White, J. (1993). Family development theory. In P. Boss, W. Doherty, R. La Rossa, W. Schumm & S. Steinmetz (Eds.), Sourcebook of

family theories and methods: A contextual approach, (pp. 225-254). New York: Plenum.

Sonnenblick, M., Friedlander, Y., & Steinberg, A. (1993). Dissociation between the wishes of terminally ill parents and decisions by their offspring. Journal of the American Geriatrics Society, 41, 599-604.

Svenson, O. & Benthorn, L. (1992). Consolidation processes in decision making: Post-decision changes in attractiveness of alternatives. Journal of Economic Psychology, 13, 315-327.

Tinsley, B., Holtgrave, D., Reise, S., Erdley, C., & Cupp, R. (1995). Developmental status, gender, age, and self-reported decision-making influences on students' risky and preventive health behaviors. Health Education Quarterly, 22(2), 244-259.

U.S. Bureau of the Census (1990). Statistical abstract of the United States: 1991. Washington, DC: United States Department of Commerce.

Walker, L. (1984). Sex differences in the development of moral reasoning. A critical review. Child Development, 55, 677-691.

Zweibel, N. & Cassel, C. (1989). Treatment choices at the end of life: A comparison of decisions by older patients and their physician-selected proxies. The Gerontologist, 29(5), 615-621.

CHAPTER V

AGEIST ATTITUDES AT END OF LIFE: THE CASE FOR PHYSICIANS AS ADVOCATES

MANUSCRIPT FOR PUBLICATION

JOURNAL TITLE: JOURNAL OF FAMILY PRACTICE

Abstract

Physicians have a unique role in supporting patients and families throughout their lives. Their expertise is called upon not only in life, but also at its end. This study, grounded in theories of moral development, was designed to determine the effect of age on life support choices for others. Additionally, gender and attachment were considered as factors which might affect the choice made for another. A sample of students, city workers, and residents of a retirement community completed the researcher developed instrument. The instrument consisted of demographic information, a social desirability scale, and seven vignettes for which the respondent chose age, gender, and life support option for a described patient. The results suggest that the least aggressive support options are chosen for the elderly. Gender and attachment had no effect on the level of care chosen. Factors cited for the lack of support include a long life and that the decider was certain of the individual's wishes. To ensure their elderly patients remain as autonomous as possible, physicians must be advocates for this special group.

AGEIST ATTITUDES AT END OF LIFE: THE CASE FOR PHYSICIANS AS ADVOCATES

The role of the physician in life support appears to be uncertain as society demands more patient autonomy and the courts erode the role of clinical decision-making (Mason & Smith, 1983). Kennedy (1984) states that the doctor has no greater expertise than the layman in dealing with ethical issues. While they may not have more expertise, it can be argued they have greater experience since they deal with life and death on a daily basis.

The physician's role in the patient's death has traditionally been to provide comfort, information, and to carry out the patient's wishes. In order for those wishes to be clearly elucidated, it is essential that the physician take the initiative in discussions of advance directives, ensuring they are informed and realistic (Lo, 1989). The ideal time for such a dialogue is the first office visit, during the history taking. Once the topic is broached, further explorations can take place as the patients preferences for feedings, antibiotics, blood transfusions and CPR are defined (Herbst, Lynn, Mermann, & Rhymes, 1995). Indeed, it is incumbent upon the physician to hold these discussions while patients are still competent, to urge them to choose a surrogate and indicate precisely how much discretion the surrogate will be allowed (Lo, 1989; Lo, Rouse, & Dornbrand, 1990). If physicians do not take the lead in promoting advance directives, they are in essence abdicating their duty to the patient and leaving a window of opportunity for challenge by hospitals, families, and the courts.

The decade of the 1990s is ushering in a relatively new context for medical decision-making. Until very recently, patients have been expected and usually quite willing to comply with the "Doctor Knows Best" status quo. Traditional paternalistic attitudes are being replaced with shared decision-

making between doctor, patient, and oftentimes, family members (Fowler, 1989). Additionally, in the past two decades there has been an increasing emphasis on patient rights and the concept of autonomy. Autonomy has at its roots principles of self-determination and self governance in all situations (Calman, 1988). A dilemma arises when the patient is old and viewed as incompetent to make autonomous choices regarding care and treatment.

Typical bioethical models focus on patient autonomy as the central element of the paradigm. Crabtree and Caron-Parker (1991) enumerated three models from which the foundation of current ethics derives. First, the medical model assumes that the acutely ill patient can be cured or compensated for any losses incurred due to the illness. Secondly, the contractual model mirrors any other business transaction; the patient is assumed to voluntarily comply with the actions of the health care provider. Thirdly, the humanist model assumes individuals act as rational, free agents, able to choose medical services in their own best interests.

Current research is investigating care and justice considerations used in ethical dilemmas when making medical decisions for self or family versus others (Peter & Gallop, 1994). This research contributes to the knowledge base regarding the reasons behind decisions but does not address whether the decisions would be the same for different aged patients or across age groups. Additionally, the role of gender in decision-making is not addressed.

While much attention is given to ethics, very little to date has related ethical decision-making with possible ageism (Moody, 1992). As technology supersedes our current ethical orientation, it is crucial that the issues of ageism and ethics be studied as a whole, rather than simply two parts. It is important to ensure that medical decision-making is truly based on ethical principles and not on one's own perception of who is entitled to treatment.

In light of an aging population, it is critical to make treatment determinations which will be fair and equitable across generations and not favor the young, simply because it is presumed they have not only so much more time, but also more right to live.

Purpose of the Study

The purpose of the study is to determine if age and gender of the patient, as well as level of attachment one has to the patient affect the outcome of a medical decision made for that particular patient. Additionally, personal characteristics of the decision maker including age, religious beliefs, family composition, and gender will be assessed as they relate to the medical decision chosen.

Review of Literature

In an effort to ensure the rights of individuals, all health care institutions which accept federal funding are now required to ascertain on admission if the patient has a living will, also called an advance directive (AD). The Patient Self Determination Act (PSDA) of 1990 applies not only to hospitals but also to nursing homes, hospices, and home health agencies. In addition to inquiring about the existence of the directive, these agencies are mandated to implement policies regarding recognition of an AD, as well as to educate their staff and the community at large about living wills (High, 1993).

Characteristics of Advance Directives and Their Use

One of the assumptions of the PSDA is that patients will execute a living will if they are given enough information and encouragement (High, 1993). Despite a federal law and community education efforts, the use of advance directives remains limited. In 1989, prior to the PSDA, Zweibel and Cassel (1989) reported only 4-15% of people in the U. S. had a living will and most of them were older adults. In 1995, that number is only 20%, a minimal

increase by even the most generous standards (Herbst, Lynn, Mermann, & Rhymes, 1995).

Though one study showed the elderly were willing to discuss advance directives, they were still infrequently used. More importantly, even when the person had completed one, their personal physician was unaware of its existence (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991). Two preliminary studies of people over age 60 indicate advance directives are not being used, even though the study participants had high levels of familiarity with and understanding of them (High, 1993). An important finding from the same study is that people who attend an instructional meeting and are given assistance with preparation are more likely to complete an advance directive (High, 1993).

As might be expected, there is also experimental evidence which indicates major differences in outcomes dependent upon the way choices are presented. For example, patients are much less likely to opt for a procedure which is presented with an 80% mortality rate than for one in which they are told 20% of all people survive the treatment (Malloy, Wigton, Meeske, & Tape, 1992). These two studies highlight the need for further community education and standardized language in advance directives.

As evidenced by the limited use of advance directives, there are still some very real barriers to their implementation. The completing of an advance directive requires decisional capacity and simulates future hypothetical medical situations (Diamond, Jernigan, Moseley, Messina, & McKeown, 1989; Malloy et al., 1992). The nature of the process forces patients to contemplate the end of their life, an experience which can be unsettling at best.

Zweibel and Cassel (1989) outlined four additional requirements: 1) prioritize qualities of life one values; 2) understand how those qualities might be threatened during illness; 3) understand available treatment options; and, 4) comprehend the implications of choice and refusal of various treatment options (p. 620). These requirements are complex, evoking spiritual and emotional responses more often than intellectual decisions.

Because the response to one's own death is often so emotional, even when advance directives are completed, it is frequently with vague, ambiguous or general preferences rather than specific treatment choices (Lo, 1989). If choices are stated clearly, it is still unrealistic to believe the advance directive can anticipate all future decisions. Lo (1989) has suggested that to be meaningful, the directive requires a series of mutual discussions with patient and physician and perhaps family, rather than a single declaration by the patient.

One tool which is becoming increasingly popular is the values history form. While this is not a legally binding document, it helps the patient and family explore wishes and attitudes regarding life and death and can lead to meaningful dialogue prior to completing the advance directive (Schroeder-Mullen, 1995). Even if uncomfortable, dialogue and completion of the directive may prevent having to make perhaps an even more onerous choice, that of terminating life support (Skegg, 1984).

To help ensure autonomy and not being forced to receive unwanted treatment, options beyond the living will also need to be presented to patients and the public. By definition, the living will specifies a patient's wishes about medical treatment to prolong life, only in cases of terminal illness (less than 6 months to live) or when death is imminent. A step beyond is the durable power of attorney for health care or designation of a proxy. This ensures that

the person the patient chooses will make decisions for them should they become incompetent to do so. A living will may include a provision for a proxy but it is not yet standardized (Schroeder-Mullen, 1995). An additional area which lacks uniformity is people's attitudes to living wills.

Attitudes Regarding Advance Directives

As might be expected, responses to living wills vary widely, and there is no significant predictor of interventional preference. In a study of 405 patients, Emanuel and colleagues found no correlation between age of respondent, health status, education, or any other demographic factor to a chosen intervention (Emanuel et al., 1991). What is consistent is the belief that a living will should be legally binding (Genuis, Genuis, & Chang, 1994; Lo, 1989). One interesting finding is that 41% of respondents who identified themselves as religiously active were opposed to making living wills legally binding (Genuis et al, 1994). No reasons were given for this particular preference and to speculate on them might lead to erroneous conclusions regarding this minority subset. Paradoxically, though 74% of respondents felt directives should be legally binding, only 46% felt hospitals should require executing one on admission (Genuis et al, 1994). The belief that hospitals should not require advance directives (though mandated to inquire about their existence) coupled with their limited use leads to questions about why they are not more prevalent.

Barriers to Use

As previously mentioned, most people, especially the elderly are comfortable deferring medical decisions to their physician. A natural outgrowth of this idea is the belief that the physician will take the initiative in discussing an advance directive if one is needed (Emanuel et al., 1991; High, 1993). Other reasons cited for not preparing a directive include feeling

it is too early to plan, believing the issue is only relevant for people who are older or in poor health, and perceiving barriers to execution such as cost, availability of witnesses or a notary (Emanuel et al., 1991; High, 1993). The most frequently cited reason for not executing a living will is the expectation that others, presumably family and physicians, will handle the issue when the time comes. This attitude reflects a widespread confidence that people can rely on others in crisis situations (High, 1993).

The most important implication for research and public policy is the least cited barrier to use; lack of knowledge or sensitivity to the topic (Emanuel et al., 1991). People are obviously cognizant of the issue yet still find reasons to put off preparing a directive, expecting family to perform as surrogates if necessary.

Role of Families and Surrogates

Surrogates are expected to base their decisions on one of two ethical principles: substituted judgment or best interest. Substituted judgment is assumed to be just that - the judgment the patient would make in the given situation. It is based closely on the known values and preferences of the patient and is considered a mirror of their own decision. Best interest is somewhat more complicated. To act in someone's best interest, data such as prospects for survival, improvement and recovery and the burden that process imposes in terms of dignity, financial cost, and physical pain to the patient all must be considered (Capron, 1994).

The concept of patient's best interest is both delicate and emotionally charged. It is frequently emotionally easier for physicians and families to justify the withholding of treatment because of their belief that the patient would not want it rather than to take personal responsibility for that decision. In judging patient's best interest, surrogates must be compelled to view best

interest from the patient's perspective and not ascribe their own preferences to the patient (Lo, 1989).

Family members are assumed to be appropriate surrogates and to act in the patient's best interest (Lo, 1989; Lo, Rouse, & Dornbrand, 1990). More often than not, a very close family member such as a spouse or adult child is chosen to be the surrogate decision maker. Findings from a study of people with and without directives were virtually identical; fifty-eight percent of respondents with an advance directive chose an adult child as proxy while 61% without a directive made that choice. Figures for the spouse as proxy were 21% and 29% respectively. As might be expected, if participants were married, 84% chose their spouse as proxy indicating confidence that they would know their preferences or act in their best interest (High, 1993).

Scholars disagree on the rights of proxies. Calman (1988) asserts that while relatives do have a right to be involved in patient care, they do not have the right to determine treatment or what is told to the patient. In direct opposition, Lo (1989) believes that families must be allowed to exercise discretion in interpreting patient preferences and best interest. A noted ethicist, Brody, states the right of the family to refuse care for the patient is in fact a delegated authority from the patient to the family so they can exercise the patient's right on their behalf (Brody, 1988).

Research supports that in the absence of direct discussion with the patient, substituted decision-making is not likely to correspond to their preferences (Danis, Southerland, Garrett, Smith, Hielema, Pickard, Egner & Patrick, 1991; Emanuel et al., 1991; Diamond et al., 1989; Zweibel & Cassel, 1989). Diamond and colleagues (1989) found 45% of proxies had prior discussions with patients regarding life sustaining treatment and 70% felt

very sure of their substituted judgment. Unfortunately, there were discrepancies in patient and proxy data 30% of the time (Diamond et al, 1989).

Informal advance direction did not improve the effectiveness of proxies in a study by Zweibel and Cassel (1989). Proxies made decisions opposite to patient preference from 24-50% of the time, depending on the intervention under discussion. Of the pairs who differed on initiation of cardiopulmonary resuscitation (CPR), 70% of the proxies asked for a do not resuscitate (DNR) order while the patients request was to be resuscitated. This finding is collaborated by Danis and colleagues who found family members consistently preferred to have life sustaining treatments withheld from the patient more frequently than the competent patients did for themselves (Danis et al., 1991).

In an Israeli study of adult children and their parents, 52% of proxies claimed they knew the patient's wishes with regard to life support and treatment preference but only 46% subsequently requested that those wishes be followed (Sonnenblick, Friedlander & Steinberg, 1993). In a culture which places less emphasis on autonomy, it is not surprising that only 50% of the adult children believed their competent parent should be involved in the decision-making process, believing that exposure to a grave dilemma might impose an unbearable burden.

As can be inferred from these research findings, quality of life judgments by surrogates can be particularly suspect. Though proxy decisions are often at odds with patient preferences, there does, however, tend to be a high correlation of personal treatment preferences and the choice made for others with congruence rates of 93-95% (Sonnenblick et al., 1993; Zweibel & Cassel, 1989).

The literature indicates family, even with the best of intentions, are not always well informed and consistent surrogates. Adult children and physicians frequently rate the quality of life of an older person lower than the people do themselves, leading to increased frequency of withholding life supporting treatments (Zweibel & Cassel, 1989). Additionally, in some families, there may be conflicts of interest between the proxy and patient or between family members. Conflicts may include being unwilling to listen to others and to recognize one's own bias, not having the patient's best interest at heart, and problems with decision-making, including being too involved to be objective (Lo, 1989). Whether decisions are made by patients, physicians, or proxies, there is ultimately a choice made and natural consequences which follow.

End of Life Decisions

As previously noted, physicians and families commonly base their decisions on previous statements by patients, inferring from these that they are making a substituted judgment or acting in the patient's best interest. In reality, those statements are being interpreted in the revealing light of a specific clinical situation. The specific situation is as much a part of the context of the decision as the values and character traits of the decider. To assume that one can decide in any given situation what a patient would want, based on their past behavior, assumes an unrealistic degree of consistency in the person's life and previous decisions (Lo, 1989). It is preferable to complete a directive in as specific terms as possible and then for it to be followed to guarantee contiguous autonomy.

An example of inconsistent decision-making can be found in a study of elderly outpatients. Though frequently cited as wanting CPR, once the information on CPR survival rates (5-30%) is given to them, the majority

refuse this option (Herbst et al., 1995). Emanuel and colleagues (1991) found no difference in patients' rates of refusal for high tech interventions as compared to simple tube feedings and hydration. Patients made no distinction between ordinary and extraordinary means and none between short term and protracted care, factors that would typically be considered by surrogates acting in the patient's best interest (Emanuel et al., 1991). Full agreement is not reached on the issue of pain medication; nearly 78% of patients want continued pain medication, even if it hastens death, while only 58% of their surrogates would choose this option for them (Emanuel et al., 1991; Sonnenblick et al., 1993).

Estimates of treatment consistency with patient decisions and advance directives range from 33-75% (Danis et al., 1991). Disturbingly, this consistency was less likely to occur when a directive was present in the medical record than when it was absent (Danis et al., 1991). Several factors are involved in the process which can lead to the directive not being followed.

One likely factor previously mentioned is that providers are frequently unaware of the existence of directives. Further, the provider may feel that the initial preference was too restrictive to allow for care which is believed to be appropriate at the time. Alternatively, the treatment chosen may, in the provider's view, afford little benefit to the patient. Finally, families may contradict the advance directive (Danis et al., 1991).

Since incompetent patients are four times more likely to receive treatment inconsistent with their wishes (Danis et al, 1991), it would appear that appointing a trusted person as proxy would be a better way to ensure continued autonomy. Without this, legal battles often ensue which cast the courts into the role of making patient care decisions, one for which they are grossly unprepared.

Methods

Previous research has focused on medical practitioners life support choices or patients' choices for themselves. This study focused on individuals' choices for family, as well as for people they do not know. Additionally, qualitative data regarding the rationale for the choice of age, gender, and life support was collected in an effort to determine if ethical constructs underlie these critical decisions.

The present study employed a combination of two methods, correlational and descriptive. The study further sought to determine the relationship between definitions of elderly and middle aged, and resultant life support decisions for others. Additionally, the relationship between gender and life support decision was explored. Finally, factors which led to the life support decision were ascertained. Relationships between these factors and level of life support chosen were described and examined in terms of patterns, trends, and common themes. The factors included age, gender and religious preference of the decider and age and gender of the person for whom the choice was made. Other factors were discovered by asking open ended questions regarding rationale for choices made. Statistical correlations were completed for this data as well.

Sample

The non-probability sample consisted of people 18 years old and older and was drawn from the following areas: 1) city workers in a large metropolitan area in the midwest; 2) residents of a retirement village; and 3) a land-grand university in the midwest. Participation was strictly voluntary and there were no inducements or punishments for participation or non-participation. The subjects remain anonymous unless they were willing to be contacted for follow up interview, which they indicated on the survey form.

In both cases, all information was kept strictly confidential and the surveys were destroyed at the completion of the project.

The sample was purposive in order to obtain sufficient numbers from various age groups. The sample was also one of convenience in order to maximize numbers of respondents using available research funds. True random sampling was not practical for this project because of the time and expense involved to gain a random sample of people 18 years old and older.

The average age of the respondent was 38 years. A clear majority (72%) were female and over one half (54%) were married. Eighty-six percent were white with some college education (50%) and were typically employed in a business or technical occupation (61%).

The data were collected by the researcher at the aforementioned sites. Prior to data collection, appropriate Institutional Review Board approvals were obtained from all involved institutions and agencies.

Research Questions

Overall questions relevant to ethical dilemmas relate to the influence of age, gender, and degree of attachment to level of life support chosen for others. Qualitative factors which lead to specific life support outcomes were also of interest.

Specific questions which guided the research effort were:

1. Does level of life support chosen decrease as age increases?
2. Does gender influence the choice one makes for another?
3. Is more aggressive life support chosen increase as level of attachment to another increases?

Variables

Independent variables which were measured include basic demographic data (i.e. age, gender, marital status, family composition,

education, occupation and religious preference). Age and education were conceived as interval level data. The remainder were nominal level.

Conventionalizing or answering questions in the way one perceives they should be answered is a significant problem in social sciences research (Edmonds, 1967). In order to determine if subjects were following what they perceive is a socially desirable pattern of responses, a social desirability scale was developed for use in conjunction with the survey. Score on the social desirability scale is an independent variable measured at the interval level. The scale uses a Likert-type format which transforms essentially nominal or ordinal data into interval level data.

Two response variables, age and gender of the vignette subject were treated as independent variables. Age was measured intervally and gender nominally.

The dependent variable was the level of life support chosen. Again, the data is essentially ordinal since the scale begins with basic treatment and becomes more complex. Since life support is conceived as a continuum, however, the data can potentially be treated intervally by assigning successive numbers to more complex treatments.

Instrument

The full text of the instrument is available from the authors. The instrument was conceived in three parts: demographics, a social desirability scale, and the seven medical decision-making vignettes.

The demographic questions were designed to obtain routine background information on the respondent and, to provide information on family characteristics such as composition, developmental stage, and roles. Though previous literature has not highlighted demographic variables as

influences on ethical dilemma resolution, the current study of lay persons in a family context did elicit different relationships.

An issue as emotionally charged as choosing life support for others has a high potential for the confounding effect of social desirability. A brief scale to determine the relationship of social desirability to life support decisions was developed by the researcher.

The scale was developed using social desirability as an overall construct. In the case of life support decision-making, three concepts or dimensions were employed to define social desirability: religiosity, attachment, and knowledge/previous experience with life support decisions. The concepts were further operationalized using four questions for each of the three categories.

Vignettes

The vignettes were researcher developed to reflect a consistent medical diagnosis and prognosis across all situations. Respondents were asked four questions at the end of each vignette: What is the age of the person? Is the person male or female? What level of life support would you choose? What factors did you consider when making this decision. The language of the life support options was adapted from Malloy, Wigton, Meeske, and Tape (1992). Their research has shown that the descriptive language can significantly influence the level of life support chosen. The language presented was clinically accurate and realistic but not clinically obscure or negative. Seven forms of the instrument were offered to reduce presentation bias.

Reliability and Validity of the Instrument

Both the social desirability scale and the vignettes used in the current study were researcher developed. The vignettes were assessed for face validity by three physicians and three registered nurses.

Reliability coefficients were computed for the social desirability scale and for each subscale. The Cronbach's alpha for the total scale was .2403: for the religiosity subscale, .4733: for the attachment subscale, .1857, and for the knowledge subscale, .2427. The values for the attachment and knowledge subscales suggest that perhaps there is more than one construct being measured by the subscale. Further testing and refinement of the scale and subscales is indicated by these results.

Procedure

The researcher obtained access to the sites previously described. On the specified day, the researcher visited the sites to administer the instrument to volunteer participants. At that time, instructions were given to the participants and questions were answered. All participants received a survey booklet and a separate sheet of life support definitions to assist them in responding to the vignettes. There were no research assistants so that the information provided to all groups was the same. Participants may have elected to identify themselves on the instrument if they were willing to be contacted for a follow-up interview. All interviews were conducted by the researcher and the information obtained is held strictly confidential.

Data Analysis

Correlational studies were completed to determine variable interrelationships. Because most of the relationships addressed included data which was ordinal and interval, Spearman Rank correlations were used for the majority of the analysis.

For some of the data which included nominal and ordinal variables, the ordinal were converted to nominal and contingency coefficients were obtained. This resulted in a more conservative estimate than either the Spearman or Pearson methods and decreased the likelihood of identifying

Reliability coefficients were computed for the social desirability scale and for each subscale. The Cronbach's alpha for the total scale was .2403: for the religiosity subscale, .4733: for the attachment subscale, .1857, and for the knowledge subscale, .2427. The values for the attachment and knowledge subscales suggest that perhaps there is more than one construct being measured by the subscale. Further testing and refinement of the scale and subscales is indicated by these results.

Procedure

The researcher obtained access to the sites previously described. On the specified day, the researcher visited the sites to administer the instrument to volunteer participants. At that time, instructions were given to the participants and questions were answered. All participants received a survey booklet and a separate sheet of life support definitions to assist them in responding to the vignettes. There were no research assistants so that the information provided to all groups was the same. Participants may have elected to identify themselves on the instrument if they were willing to be contacted for a follow-up interview. All interviews were conducted by the researcher and the information obtained is held strictly confidential.

Data Analysis

Correlational studies were completed to determine variable interrelationships. Because most of the relationships addressed included data which was ordinal and interval, Spearman Rank correlations were used for the majority of the analysis.

For some of the data which included nominal and ordinal variables, the ordinal were converted to nominal and contingency coefficients were obtained. This resulted in a more conservative estimate than either the Spearman or Pearson methods and decreased the likelihood of identifying

potentially spurious relationships. The relationship of qualitative factors and life support choices was analyzed using a one way ANOVA with post-hoc analysis employing the Scheffe test.

Results

Respondents were presented with seven different situations in which the age of the patient varied. The instructions asked the respondent to specify the age of the person in each situation, with the supplied information indicating only that the person was a child, middle-aged, or elderly.

In situation one, the older the spouse, the more likely they were to receive nutrition only, versus a more vigorous life support alternative. Using a Spearman Rank correlation (because life support data is ordinal while age is interval/ratio), the results are significant with a p value $\leq .01$. This result indicates a strong correlation with age of spouse (M=43.27) and life support choice (see Table 4).

Insert Table 4 about here

Situation two concerned the age of one's child. There was no significant correlation in the age of the child (M=15.04) with any given life support choice. This is the only situation in which full CPR was selected more than nutrition only. Most respondents chose full CPR, regardless of the age of the child. Qualitative comments from the respondents indicated a high value placed on the life of any child, no matter what his or her age.

Situation three described the scenario with an elderly parent. Older parents did not receive full CPR but were given nutrition only as their life support. This result was significant at $p \leq .01$, indicating a strong correlation between the age of the parent (M=72.68) and the nutrition option.

potentially spurious relationships. The relationship of qualitative factors and life support choices was analyzed using a one way ANOVA with post-hoc analysis employing the Scheffe test.

Results

Respondents were presented with seven different situations in which the age of the patient varied. The instructions asked the respondent to specify the age of the person in each situation, with the supplied information indicating only that the person was a child, middle-aged, or elderly.

In situation one, the older the spouse, the more likely they were to receive nutrition only, versus a more vigorous life support alternative. Using a Spearman Rank correlation (because life support data is ordinal while age is interval/ratio), the results are significant with a p value $\leq .01$. This result indicates a strong correlation with age of spouse (M=43.27) and life support choice (see Table 4).

Insert Table 4 about here

Situation two concerned the age of one's child. There was no significant correlation in the age of the child (M=15.04) with any given life support choice. This is the only situation in which full CPR was selected more than nutrition only. Most respondents chose full CPR, regardless of the age of the child. Qualitative comments from the respondents indicated a high value placed on the life of any child, no matter what his or her age.

Situation three described the scenario with an elderly parent. Older parents did not receive full CPR but were given nutrition only as their life support. This result was significant at $p \leq .01$, indicating a strong correlation between the age of the parent (M=72.68) and the nutrition option.

potentially spurious relationships. The relationship of qualitative factors and life support choices was analyzed using a one way ANOVA with post-hoc analysis employing the Scheffe test.

Results

Respondents were presented with seven different situations in which the age of the patient varied. The instructions asked the respondent to specify the age of the person in each situation, with the supplied information indicating only that the person was a child, middle-aged, or elderly.

In situation one, the older the spouse, the more likely they were to receive nutrition only, versus a more vigorous life support alternative. Using a Spearman Rank correlation (because life support data is ordinal while age is interval/ratio), the results are significant with a p value $\leq .01$. This result indicates a strong correlation with age of spouse (M=43.27) and life support choice (see Table 4).

Insert Table 4 about here

Situation two concerned the age of one's child. There was no significant correlation in the age of the child (M=15.04) with any given life support choice. This is the only situation in which full CPR was selected more than nutrition only. Most respondents chose full CPR, regardless of the age of the child. Qualitative comments from the respondents indicated a high value placed on the life of any child, no matter what his or her age.

Situation three described the scenario with an elderly parent. Older parents did not receive full CPR but were given nutrition only as their life support. This result was significant at $p \leq .01$, indicating a strong correlation between the age of the parent (M=72.68) and the nutrition option.

Respondent occupation was found to be significant in only one scenario, that of the middle-aged co-worker (Spearman correlation = .2281, N=150, $p \leq .002$). However, further analysis using age as a co-variate found no relationship between occupation and life support choices.

Religious preference of the respondent had no relationship to life support options chosen in any of the scenarios. Likewise, gender of the respondent was not related to his or her decisions regarding life support for others.

Qualitative Factors

In all, each of 151 respondents was asked to make a life support choice for each of seven different scenarios, for a total of 1057 responses. Additionally, they were asked to list factors which shaped their particular decision in each case. From this large pool of potential responses, only 15 different reasons (including none or blank) emerged as the basis for the life support choice.

For the majority of the responses, there was a presumption that the wishes of the patient were clearly known to the decider. This logically assumes that families are having conversations about end of life issues and personal preferences. Unfortunately, neither the current scholarship nor anecdotal reports support this view. More commonly, family members tend to bicker among themselves about life support options, with each member claiming to know what the patient wants. Sadly, this most often takes place in a time of great personal strain on the entire family and the life support choice becomes the stage where feelings of guilt and shame, as well as issues of control are acted out.

The other qualitative factor which is somewhat suspect states that the person has no potential for quality of life. This suggests a sweeping over-

simplification of what constitutes life quality as well as measures each individual life by the same collective yardstick.

While one family or family member may believe that a person in coma who cannot respond has no potential quality of life, another family may delight in sitting at the bedside, sharing stories, and touching their loved one, thus, having the quality of their own lives enhanced. Because a person may not be sitting up talking and taking nourishment does not preclude that they are contributing to the family in a very real and dynamic way. If one can be moved simply by looking at a museum painting, how much more can be gained by gazing at a loved one who is a part of one's own self?

Certain factors appear to be related to specific life support choices. Factors expressing hope, personal feelings, morality and potential contribution were related to full CPR. Perceived lack of quality of life, assumption of the patient's preferences and belief in the physician's stated prognosis were related to less aggressive life support (nutrition only).

Discussion

Clearly, this study suggests that older people are less likely to receive full life support measures. These results are consistent with previously cited research in which less aggressive support was chosen for older adults, often at odds with their own preference. This lack of support can be attributed to ageism, a prevailing norm in our society. The older person's physician is in a strong position to advocate for successful aging on their behalf.

Successful aging should be in the eye of the ager (or beholder, as it were). Every day, trite and obvious examples of what is purported to be successful aging (but are really just gray-haired people doing typically "youthful" things) occur in the media. On TV, one is bombarded with 80 year old parachutists and lovely, silver couples emerging from the ocean in full

scuba gear, bellying up to the beach bar for the "right" nutrition supplement. Needless to say, the frumpy couple under the umbrella are imbibing in the "wrong" beverage. This is, on some level, a positive representation of later life, but sadly, is based on images typically associated with youth.

The media blitz may be able to alter our perception of senior's capabilities, but the reality is, their true capabilities have not altered at all. There have always been 75 year old master swimmers, artists, writers, joggers, and intellectuals. And, there have always been 75 year olds who are not doing these things and are aging successfully. They continue to be good parents, wonderful grandparents, tried and true friends, and siblings. They cook meals, have hobbies, vote their conscience, and don't kick their dogs. They are happy. In whose eyes would that not be considered successful? Jumping out of a perfectly good airplane does not make one any more successful at 80 than it does at thirty.

Implications

With time a precious resource in a busy medical practice, the physician must make the most of any opportunity to provide information about advance directives to their elderly patients. Information can be provided in a tiered system, which makes the most of physician and employee time.

An often overlooked opportunity is to use the waiting room to provide important information. Most states, as well as several of the medical literature companies, publish flyers on advance directives. The advantage to the state materials is that they contain the subtle nuances in description and language which can vary from state to state. Another effective strategy is to post a sign in the exam room, asking if the patient has an advance directive or would like information on how to complete one.

A step up in involvement would include the nurse or medical assistant asking the patient at intake if they have completed an advance directive or, need to update the one that is on file. Since the inception of the Patient Self Determination Act in 1990, this strategy is used in all facilities which accept Medicare funding so the patient is somewhat accustomed to the question. Properly trained office staff can assist a patient and family with completing the document or can make an appropriate referral (usually to the hospital social work department). The final level of involvement would include the physician who would be able to answer more in depth questions about end of life management.

As medicine shifts to a more primary care focus, the family physician has a unique opportunity to initiate discussions regarding life itself, as well as life support with patients and families. As health status changes, the physician can open discussions with patients regarding any changes in lifestyle and in eventual life support which might be advised. With honest communication, in an atmosphere free of ageist attitudes, older adults can make final choices with dignity and grace. And, the physician can be honored to have participated in all phases of their lives.

References

Brody, B. A. (1988). Life and death decision making. New York: Oxford University Press.

Calman, K. C. (1988). Ethical implications of terminal care. In M. Freeman, (Ed.), Medicine, ethics and the law. London: Stevens & Sons.

Capron, A. M. (1994). Life's sacred value-Common ground or battleground? Michigan Law Review, 92(6), 1491-1502.

Crabtree, J. L. & Caron-Parker, L. M. (1991). Long-term care of the aged: Ethical dilemmas and solutions. The American Journal of Occupational Therapy, 45(7), 607-612.

Danis, M., Southerland, L., Garrett, J., Smith, J., Hielema, F., Pickard, C., Egner, D., & Patrick, D. (1991). A prospective study of advance directives for life-sustaining care. The New England Journal of Medicine, 324(13), 882-888.

Diamond, E., Jernigan, J., Moseley, R., Messina, V. & McKeown, R. (1989). Decision-making ability and advance directive preferences in nursing home patients and proxies. The Gerontologist, 29(5), 622-626.

Emanuel, L., Barry, M., Stoeckle, J., Ettelson, L. & Emanuel, E. (1991). Advance directives for medical care: A case for greater use. The New England Journal of Medicine, 324(13), 889-895.

Fowler, M. (1989). Ethical decision making in clinical practice. Nursing Clinics of North America, 24(4), 955-965.

Genuis, S., Genuis, S., & Chang, W. (1994). Public attitudes toward the right to die. Canadian Medical Association Journal, 150(5), 701-708.

Herbst, L., Lynn, J., Mermann, A., & Rhymes, J. (1995). What do dying patients want and need? Patient Care, February 28, 27-35, 39.

High, D. (1993). Advance directives and the elderly: A study of intervention strategies to increase use. The Gerontologist, 33(3), 342-349.

Kennedy, I. (1984). The law relating to the treatment of the terminally ill. In C. Saunders (Ed.). The management of terminal malignant disease. New York: Edward Arnold.

Lo. B. (1989). Caring for incompetent patients: Is there a physician on the case? Law, Medicine & Health Care, 17(3), 214-220.

Lo., B., Rouse, R., & Dornbrand, L. (1990). Family decision making on trial. The New England Journal of Medicine, 322(17), 1228-1232.

Malloy, T., Wigton, R., Meeske, J., & Tape, T., (1992). The influence of treatment descriptions on advance medical directive decisions. Journal of the American Geriatrics Society, 40, 1255-1260.

Mason, J. & Smith, R. (1983). Law and medical ethics. London: Butterworths.

Moody, H. R. (1992). Ethics in an aging society. Baltimore, MD: The Johns Hopkins University Press.

Peter, E. & Gallop, R. (1994). The ethic of care: A comparison of nursing and medical students. Image, 26(1), 47-51.

Schroeder-Mullen, H. (1995). Keeping up with advance directives. Patient Care, February 28, 12.

Skegg, P. (1984). Law, ethics, and medicine. Oxford: Clarendon Press.

Sonnenblick, M., Friedlander, Y., & Steinberg, A. (1993). Dissociation between the wishes of terminally ill parents and decisions by their offspring. Journal of the American Geriatrics Society, 41, 599-604.

Zweibel, N. & Cassel, C. (1989). Treatment choices at the end of life: A comparison of decisions by older patients and their physician-selected proxies. The Gerontologist, 29(5), 615-621.

Bibliography

Allmark, P. (1992). The ethical enterprise of nursing. Journal of Advanced Nursing, 17(1), 16-20.

Aldous, J. (1978). Family careers: Developmental change in families. New York: Wiley.

Andrews, F. M., Klem, L., Davidson, T. N., O'Malley, P. M. & Rodgers, W. L. (1981). A guide for selecting statistical techniques for analyzing social science data. Second edition. The University of Michigan: Institute for Social Research.

Barondess, J. A., Kalb, P., Weil, W. B., Cassel, C. (1988). Clinical decision making in catastrophic situations: The relevance of age. Journal of the American Geriatrics Society, 36(10), 919-937.

Becker, M. H. (Ed.). (1974). The health belief model and personal health behavior. Health Education Monographs, 2(4).

Berger, M. C., Seversen, A. & Chvatal, R. (1991). Ethical issues in nursing. Western Journal of Nursing Research, 13(4), 514-521.

Bierman, H. (1989). A behavioral decision theory paradox. Behavioral Sciences, 34, 286-288.

Billig, M. (1991). Ideology and opinions. Studies in rhetorical psychology. London: Sage.

Brody, B. A. (1988). Life and death decision making. New York: Oxford University Press.

Busemeyer, J. R. & Myung, I. J. (1992). An adaptive approach to human decision making: Learning theory, decision theory, and human performance. Journal of Experimental Psychology: General, 121(2), 177-194.

Callahan, D. (1988). Families as caregivers: The limits of morality. Archives of Physical Medicine and Rehabilitation, 69, 323-328.

Calman, K. C. (1988). Ethical implications of terminal care. In M. Freeman, (Ed.), Medicine, ethics and the law. London: Stevens & Sons.

Capron, A. M. (1994). Life's sacred value-Common ground or battleground? Michigan Law Review, 92(6), 1491-1502.

Clark, P. G. (1991). Ethical dimensions of quality of life in aging: Autonomy vs. collectivism in the United States and Canada. The Gerontologist, 31(5), 631-639.

Constitution and Bill of Rights of the United States, Constitutional Convention, Philadelphia, 1787.

Cooper, M. C. (1989). Gilligan's different voice: A perspective for nursing. Journal of Professional Nursing, 5(1), 10-16.

Crabtree, J. L. & Caron-Parker, L. M. (1991). Long-term care of the aged: Ethical dilemmas and solutions. The American Journal of Occupational Therapy, 45(7), 607-612.

Crisham, P. (1981). Measuring moral judgment in nursing dilemmas. Nursing Research, 30, 104-110.

Cruzan v. Director, Mo. Dept. of Health, 497 U.S. 261,284 (1990).

Czerwinski, B. S. (1990). An autopsy of an ethical dilemma. Journal of Nursing Administration, 20(6), 25-29.

Danis, M., Southerland, L., Garrett, J., Smith, J., Hielema, F., Pickard, C., Egner, D., & Patrick, D. (1991). A prospective study of advance directives for life-sustaining care. The New England Journal of Medicine, 324(13), 882-888.

Davis, A. J. (1981). Ethical dilemmas in nursing: A survey. Western Journal of Nursing Research, 3, 397-407.

Declaration of Independence. Second Continental Congress, July 4, 1776.

Diamond, E., Jernigan, J., Moseley, R., Messina, V. & McKeown, R. (1989). Decision-making ability and advance directive preferences in nursing home patients and proxies. The Gerontologist, 29(5), 622-626.

Duckett, L., Rowan-Boyer, M., Ryden, M. B., Crisham, P., Savik, K., & Rest,

J. R. (1992). Challenging misperceptions about nurses' moral reasoning. Nursing Research 41(6), 324-331.

Dychtwald, K. & Flower, J. (1990). Age wave. New York: Bantam.

Edmonds, V. H. (1967). Marital conventionalization: Definition and measurement. Journal of Marriage and the Family, 29(4), 681-688.

Edwards, W. (1954). The theory of decision making. Psychological Bulletin, 51, 380-417.

Emanuel, L., Barry, M., Stoeckle, J., Ettelson, L. & Emanuel, E. (1991). Advance directives for medical care: A case for greater use. The New England Journal of Medicine, 324(13), 889-895.

Evans, J., Over, D., & Manktelow, K. (1993). Reasoning, decision making and rationality. Cognition, 49, 165-187.

Fishbein, M. & Ajzen, I. (1975). Belief, attitude, intention and behavior: An introduction to theory and research. Reading, MA: Addison-Wesley.

Fowler, M. (1989). Ethical decision making in clinical practice. Nursing Clinics of North America, 24(4), 955-965.

Frisch, D. & Clemen, R. (1994). Beyond expected utility: Rethinking behavioral decision research. Psychological Bulletin, 116(1), 46-54.

Genuis, S., Genuis, S., & Chang, W. (1994). Public attitudes toward the right to die. Canadian Medical Association Journal, 150(5), 701-708.

Gielen, U. (1991). Kohlberg's moral development theory. In L. Kuhlmerker with U. Gielen & R. L. Hayes (Eds.), The Kohlberg legacy for the helping professions, (pp. 18-38). Birmingham, AL: R. E. P. Books.

Gilligan, C. (1982). In a different voice. Cambridge, MA: Harvard University Press.

Hardwig, J. (1990). What about family? Hastings Center Report, March/April, 5-10.

Herbst, L., Lynn, J., Mermann, A., & Rhymes, J. (1995). What do dying patients want and need? Patient Care, February 28, 27-35, 39.

High, D. (1988). All in the family: Extended autonomy and expectations in surrogate health care decision-making. The Gerontologist, 28(Supp.), 46-51.

High, D. (1991). A new myth about families of older people? The Gerontologist, 31(5), 611-618.

High, D. (1993). Advance directives and the elderly: A study of intervention strategies to increase use. The Gerontologist, 33(3), 342-349.

Hill, R. & Hansen, D. A. (1960). The identification of conceptual frameworks used in family study. Marriage and Family Living, 22, 299-311.

Horner, J., & Miehl, J. L. (1991). The deontological decision-making model as a bioethical tool. Association of Operating Room Nurses Journal, 54(2), 208-218.

Hoyer, P. J., Booth, D., Spelman, M. R. & Richardson, C. E. (1991). Clinical cheating and moral development. Nursing Outlook, 39(4), 170-173.

In the matter of Mary O'Connor, 72 N. Y. 2nd, 517, 1988.

In re Conroy, 486 A. 2d 1209 (N. J. 1985).

Isaac, S. & Michael, W. B. (1995). Handbook in research and evaluation. Third edition. San Diego, CA: EdITS/Educational and Industrial Testing Services.

Jameton, A. (1987). Duties to self. In M. Fowler & J. Levine-Ariff, (Eds.). Ethics at the bedside: A source book for the critical care nurse, (pp. 115-135). Philadelphia: J. B. Lippincott.

Jecker, N. S. (1990). The role of intimate others in medical decision making. The Gerontologist, 30(1), 65-71.

Kadane, J. B. (1992). Healthy skepticism as an expected-utility explanation of the phenomena of Allais and Ellsberg. Theory and Decision, 32, 57-64.

Kahneman, D. & Tversky, A. (1984). Choices, values, and frames. American Psychologist, 39, 341-350.

Kapp, M. B. (1991). Health care decision making by the elderly: I get by with a little help from my family. The Gerontologist, 31(5), 619-623.

Keller, M. (1985). Nurses' responses to moral dilemmas. Doctoral dissertation, University of South Carolina. Dissertation Abstracts International, 46, 1870B.

Kennedy, I. (1984). The law relating to the treatment of the terminally ill. In C. Saunders (Ed.). The management of terminal malignant disease. New York: Edward Arnold.

Ketefian, S. (1981). Critical thinking, educational preparation and development of moral judgment among a selected group of practicing nurses. Nursing Research, 30, 98-103.

Ketefian, S. (1989). Moral reasoning and ethical practice in nursing: Measurement issues. Nursing Clinics of North America, 24, 509-521.

Kohlberg, L. (1978). The cognitive approach to moral education. In P. Scharf (Ed.), Readings in moral education (pp. 36-51). Minneapolis, MN: Winston Press.

Kohlberg, L. & Kramer, R. (1976). Continuities and discontinuities in childhood and adult moral development. In N. Endler, L. Boulter, & H. Osser (Eds.), Contemporary issues in developmental psychology, second edition. New York: Holt, Rinehart & Winston.

Kurtines, J. & Greif, E. B. (1979). The development of moral thought: Review and evaluation of Kohlberg's approach. Psychological Bulletin, 81, 453-470.

Lackman, C. & Lanasa, J. M. (1993). Family decision-making theory: An overview and assessment. Psychology and Marketing, 10(2), 81-93.

Lawrence, J. A. & Crisham, P. (1984). Making a choice. Nursing Times, July 18, 57-58.

Lo. B. (1989). Caring for incompetent patients: Is there a physician on the case? Law, Medicine & Health Care, 17(3), 214-220.

Lo., B., Rouse, R., & Dornbrand, L. (1990). Family decision making on trial. The New England Journal of Medicine, 322(17), 1228-1232.

Maddux, J. E. & Rogers, R. W. (1983). Protection motivation and self-efficacy: A revised theory of fear appeals and attitude change. Journal of Experimental Social Psychology, 19, 469-479.

Malloy, T., Wigton, R., Meeske, J., & Tape, T., (1992). The influence of treatment descriptions on advance medical directive decisions. Journal of the American Geriatrics Society, 40, 1255-1260.

Marzen, T. (1994). "Out, out brief candle": Constitutionally prescribed suicide for the terminally ill. Hastings Constitutional Law Quarterly, 21(3), 799-826.

Mason, J. & Smith, R. (1983). Law and medical ethics. London: Butterworths.

Mattessich, P. & Hill, R. (1987). Life cycle and family development. In M. Sussman and S. Steinmetz (Eds.), Handbook of marriage and the family, (pp. 437-469). New York: Plenum.

Meier, D. E. (1992). Ethical issues in geriatric medicine. In J. C. Brocklehurst, R. C. Tallis & H. M. Fillit (Eds.), Textbook of geriatric medicine and gerontology, (pp 1062-1072). Edinburgh: Churchill Livingstone.

Miles, S. H., Singer, P. A., & Siegler, M. (1989). Conflicts between patients' wishes to forgo treatment and the policies of health care facilities. The New England Journal of Medicine, 321, 48-50.

Miller, D. C. (1991). Handbook of research design and social measurement, fifth edition. London: Sage.

Miller, L. H. (1984). Alternative approaches to measuring nursing: Gilligan's and Kohlberg's moral development scales. Rehabilitation Nursing, Sept.-Oct., 22-26.

Mitchell, T. R. & Beach, L. R. (1990). ". . . Do I love thee? Let me count. . ." Toward an understanding of intuitive and automatic decision making. Organizational Behavior and Human Decision Processes, 47, 1-20.

Montgomery, H. (1994). Towards a perspective theory of decision making and judgment. Acta Psychologica 87, 155-178.

Moody, H. R. (1992). Ethics in an aging society. Baltimore, MD: The Johns Hopkins University Press.

Munhall, P. (1980). Moral reasoning level of nursing students and faculty in a baccalaureate nursing program. Image, 12, 57-61.

Nevins, M. (1986). Analysis of the supreme court of New Jersey's decision in the Claire Conroy case. Journal of the American Geriatrics Society, 34, 140-143.

Nevins, M. (1988). New Jersey's supreme court "deregulates" right to die cases. Journal of the American Geriatrics Society, 36, 476-479.

Nisbett, R. & Wilson, T. (1977). Telling more than we can know: Verbal reports on mental processes. Psychological Review, 84, 231-259.

Omery, A. (1989). Values, moral reasoning, and ethics. Nursing Clinics of North America, 24(2), 499-500.

Payton, R. (1989). Ethical decision making: Models and processes. The Oklahoma Nurse, 34(1), 8.

Peter, E. & Gallop, R. (1994). The ethic of care: A comparison of nursing and medical students. Image, 26(1), 47-51.

Rest, J. (1979). Development in judging moral issues. Minneapolis, MN: University of Minnesota Press.

Rodgers, R. & White, J. (1993). Family development theory. In P. Boss, W. Doherty, R. La Rossa, W. Schumm & S. Steinmetz (Eds.), Sourcebook of family theories and methods: A contextual approach, (pp. 225-254). New York: Plenum.

Ryden, M. B., Waithe, M. E., Crisham, P., Caplan, A. & Duckett, L. (1989). Wrestling with the larger picture: Placing ethical behavior in clinical situations in context. Journal of Nursing Education, 28(6), 271-275.

Schloendorff v. Society of New York Hospitals. 211 N. Y. 125, 127, 129; 105 N. E. 92, 93 (1914).

Schroeder-Mullen, H. (1995). Keeping up with advance directives. Patient Care, February 28, 12.

Skegg, P. (1984). Law, ethics, and medicine. Oxford: Clarendon Press.

Smith, D. & Weaver, B. (1987). Guidelines for decision making. Journal of Gerontological Nursing, 13(3), 47-48.

Smith, R., Woodward, N., Wallston, B., Wallston, K., Rye, P. & Zylstra, M. (1988). Health care implications of desire and expectancy for control in elderly adults. Journals of Gerontology, 43, P1-P7.

Sonnenblick, M., Friedlander, Y., & Steinberg, A. (1993). Dissociation between the wishes of terminally ill parents and decisions by their offspring. Journal of the American Geriatrics Society, 41, 599-604.

Svenson, O. & Benthorn, L. (1992). Consolidation processes in decision making: Post-decision changes in attractiveness of alternatives. Journal of Economic Psychology, 13, 315-327.

Tinsley, B., Holtgrave, D., Reise, S., Erdley, C., & Cupp, R. (1995). Developmental status, gender, age, and self-reported decision-making influences on students' risky and preventive health behaviors. Health Education Quarterly, 22(2), 244-259.

Tulsky, J. & Lo, B. (1992). Ethics consultation: Time to focus on patients. The American Journal of Medicine, 92, 343-345.

U.S. Bureau of the Census (1990). Statistical abstract of the United States: 1991. Washington, DC: United States Department of Commerce.

Walker, L. (1984). Sex differences in the development of moral reasoning. A critical review. Child Development, 55, 677-691.

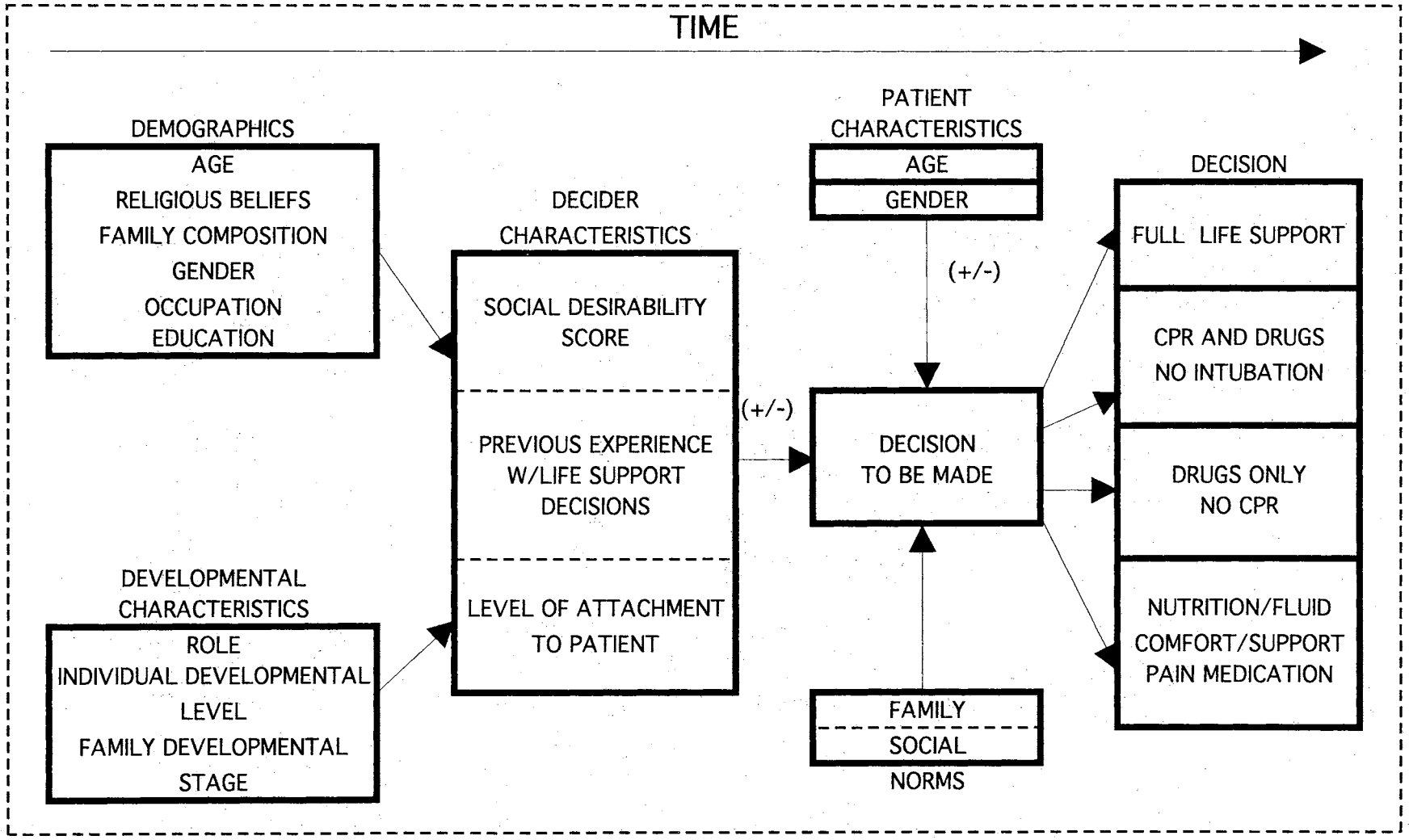
Weinstein, N. (1993). Testing four competing theories of health-protective behavior. Health Psychology, 12(4), 324-333.

Zucker, A. & Annarino, L. (1986). Department of law and ethics. Death Studies, 10, 191-195.

Zweibel, N. & Cassel, C. (1989). Treatment choices at the end of life: A comparison of decisions by older patients and their physician-selected proxies. The Gerontologist, 29(5), 615-621.

APPENDIX A

RESEARCH MODEL



FAMILY DEVELOPMENTAL MODEL OF LIFE SUPPORT DECISION MAKING

APPENDIX B

RESEARCH INSTRUMENT

#_____

Life Support Survey

Please fill in the general information below. If you have any questions, please do not hesitate to ask.

1. What is the month and year of your birth?_____

2. What is your gender? Check one: ___Male or ___Female

3. Relationship status: Check one:

_____Married _____Co-habitating

_____Divorced _____Widowed

_____Separated _____Never married

4. Religious preference_____

5. Ethnicity: Check one:

_____African American _____Caucasian

_____Hispanic _____Native American

_____Pacific Islander

6. How many children do you have?_____

How many are boys?_____

How many are girls?_____

7. Place a check mark by your educational preparation:

_____ Completed some high school

_____ Completed high school

_____ Completed some college

_____ Completed Associate's degree

_____ Completed Bachelor's degree

_____ Completed Master's degree

_____ Completed Ph.D. or other professional degree

8. What is your current occupation? If you are retired, what type of work did you do?_____

9. How would you rate your current physical health status? Check only one:

_____Excellent _____Good _____Fair _____Poor

10. How would you rate your current mental/emotional health status? Check only one:

_____Excellent _____Good _____Fair _____Poor

11. How many people who live in your family are over age 18?_____

How many people who live in your family are under age 18?_____

For the following 12 questions, circle the number on the scale under the statement which best describes how you feel about that statement.

SAMPLE QUESTION

Chocolate is the best flavor of ice cream.

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

1. **I consider myself to be religious.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

2. **All human life is sacred.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

3. **There is life after death.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

4. **Money is always a consideration, even when a life is at stake.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

5. **Family is the most important part of my life.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

6. **People always have the right to make their own decisions.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

7. **I always ask my family for advice when making decisions.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

8. **Career decisions always come first for me.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

9. **Death on TV is realistic.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

10. **I have made life support decisions for others.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

11. **Living wills are only a guide. Family must decide life support if a member becomes incompetent.**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

12. **I have completed or plan to complete a living will (advanced directive).**

1	2	3	4	5	6	7
Definite No	No	Probably No	Uncertain	Probably Yes	Yes	Definite Yes

Use the page of Definitions of Life Support Choices to answer the following seven situations.

Situation One

Your spouse has a medical condition which has led to a coma. The physicians have told you that there is no chance for recovery beyond what you now see. Because there is no living will, you are asked to complete instructions for the medical team to use in the event that your spouse stops breathing or the heart stops beating. Check only one of the following life support options for your spouse.

_____ Full CPR

_____ CPR and drugs, no intubation

_____ Drugs only, no CPR

_____ Nutrition, fluids, pain medication and comfort measures only

What is the age of your spouse?_____

Is your spouse male or female?_____

What factors did you consider when making your decision?

Situation Two

Your child has a medical condition which has led to a coma. The physicians have told you that there is no chance for recovery beyond what you now see. You are asked to complete medical instructions for use in the event that your child stops breathing or the heart stops beating. Check only one of the following life support options for your child.

_____ Full CPR

_____ CPR and drugs, no intubation

_____ Drugs only, no CPR

_____ Nutrition, fluids, pain medication and comfort measures only

What is the age of your child?_____

Is your child male or female?_____

What factors did you consider when making your decision?

Situation Three

Your elderly parent has a medical condition which has led to a coma. The physicians have told you that there is no chance for recovery beyond what you now see. Because there is no living will, you are asked to complete medical instructions for use in the event that your elderly parent stops breathing or the heart stops beating. Check only one of the following life support options for your parent.

_____ Full CPR

_____ CPR and drugs, no intubation

_____ Drugs only, no CPR

_____ Nutrition, fluids, pain medication and comfort measures only

What is the age of your parent?_____

Is your parent male or female?_____

What factors did you consider when making your decision?

Situation Four

Your elderly neighbor has a medical condition which has led to a coma. The physicians have told you that there is no chance for recovery beyond what you now see. Because there is no family, your neighbor has designated you as the person to make all health care decisions. You are asked to complete instructions for the medical team to use in the event that your neighbor stops breathing or the heart stops beating. Check only one of the following life support options for your neighbor.

_____ Full CPR

_____ CPR and drugs, no intubation

_____ Drugs only, no CPR

_____ Nutrition, fluids, pain medication and comfort measures only

What is the age of your neighbor?_____

Is your neighbor male or female?_____

What factors did you consider when making your decision?

Situation Five

Your middle-aged co-worker has a medical condition which has led to a coma. The physicians have told you that there is no chance for recovery beyond what you now see. Because there is no family, your co-worker has designated you as the person to make all health care decisions. You are asked to complete medical instructions for use in the event that your co-worker stops breathing or the heart stops beating. Check only one of the following life support options for your co-worker.

_____ Full CPR

_____ CPR and drugs, no intubation

_____ Drugs only, no CPR

_____ Nutrition, fluids, pain medication and comfort measures only

What is the age of your co-worker?_____

Is your co-worker male or female?_____

What factors did you consider when making your decision?

Situation Six

You are on an Ethics committee at the local hospital which meets once a month to make decisions about different cases. Today you are presented with a middle-aged person who has a medical condition which has led to a coma. The physicians have told you that there is no chance for recovery beyond what you now see. Because there is no living will, you are asked to complete medical instructions for use in the event that this person stops breathing or the heart stops beating. Check only one of the following life support options for this person.

_____ Full CPR

_____ CPR and drugs, no intubation

_____ Drugs only, no CPR

_____ Nutrition, fluids, pain medication and comfort measures only

What is the age of this person?_____

Is this person male or female?_____

What factors did you consider when making your decision?

Situation Seven

You have a medical condition which has led to a coma. The physicians have told your family that there is no chance for recovery beyond what they now see. You previously completed medical instructions for use in the event that you stopped breathing or your heart stopped beating. Of the following life support options, check the one which you would chose for yourself.

_____ Full CPR

_____ CPR and drugs, no intubation

_____ Drugs only, no CPR

_____ Nutrition, fluids, pain medication and comfort measures only

What is your age?_____

Are you male or female?_____

What factors did you consider when making your decision?

#_____

Thank you for your participation in this study.

OPTIONAL

Do NOT fill out this section unless you would like to discuss your responses in a follow up interview.

Name:_____

Address:_____

City:_____

State & Zip Code:_____

Phone:__(_____)_____

APPENDIX C

ANALYSIS OF RESEARCH QUESTIONS

Research Question 1:

Does patient age affect the level of care chosen in the event the patient cannot choose?

Respondents were presented with seven different situations in which the age of the patient varied. The instructions asked the respondent to specify the age of the person in each situation, with the supplied information indicating only that the person was a child, middle-aged, or elderly.

In situation one, the older the spouse, the more likely they were to receive nutrition only, versus a more vigorous life support alternative. Using a Spearman Rank correlation (because life support data is ordinal while age is interval/ratio), the results are significant with a p value $\leq .01$. This result indicates a strong correlation with age of spouse (M=43.27) and life support choice (see Table 6).

Situation two concerned the age of one's child. There was no significant correlation in the age of the child (M=15.04) with any given life support choice. This is the only situation in which full CPR was selected more than nutrition only. Most respondents chose full CPR, regardless of the age of the child. Qualitative comments from the respondents indicated a high value placed on the life of any child, no matter what his or her age.

Situation three described the scenario with an elderly parent. Older parents did not receive full CPR but were given nutrition only as their life support. This result was significant at $p \leq .01$, indicating a strong correlation between the age of the parent (M=72.68) and the nutrition option.

Situation four concerned an elderly neighbor. The mean reported age for this elderly person was somewhat higher (M=75.29) than for the elderly

parent. There was a strong correlation ($p \leq .005$) with the age of the neighbor and the chosen life support, with older neighbors receiving nutrition only.

Situation five described a middle-aged co-worker (M=43.93). The results of correlation analysis of age and life support option were not significant at the .05 level for this scenario.

In situation six, the described person was middle-aged, in a hospital, unknown to the respondent. There was no demonstrated relationship between life support option and age (M=49.14) in this case. The age of this middle-aged person, however, is significantly older than the age of the middle-aged co-worker ($t = 46.3$, $p \leq .001$). As in situations three and four, the closer the relationship, the younger the person was chosen to be. Likewise, persons with whom the respondent were more distant were assumed to be older.

In situation seven, the respondent was asked to choose a life support option for him or herself. Consistent with the other significant results, the older the respondent was in the scenario (M=43.38), the more likely they were to choose nutrition only as a life support choice ($p \leq .001$).

In summary, in most applications, patient age does affect the level of care chosen with older ages being given the least aggressive of the life support options, while a child is usually provided the most aggressive of the supportive measures. There was no demonstrated relationship with any of the life support options and the condition of middle-age.

Research Question 2:

Does patient gender affect the level of care chosen in the event the patient cannot choose?

This question concerns one nominal variable (gender) and one ordinal variable (level of life support). For purposes of analysis, the ordinal scale was converted to a nominal scale and contingency coefficients were obtained. This results in a more conservative estimate than the Pearson or Spearman correlation methods.

In all seven scenarios, gender was not found to be a significant factor ($p \leq .05$) in the chosen life support, using contingency coefficients or Pearson's r. In situation three, however, the elderly female parents were more likely to receive full CPR ($p \leq .05$) than the elderly male parents when a Spearman correlation was employed. Though interesting, this does not change the fact that the elderly parent of either gender was more likely to be given nutrition only and the more conservative estimates found no significant relationship for gender.

Research Question 3:

Does the level of attachment to a patient affect the level of care chosen?

Prior to data collection, attachment was thought to correlate highly with the level of life support one would choose for another, with closer relationships resulting in more complex or heroic life support measures. Though no statistically significant relationship was found in the choice of life support for others based on attachment ($p \leq .05$), certain qualitative factors regarding personal feelings emerged as significant in relation to choices (see Research Question 4).

Research Question 4:

What qualitative factors are considered in making medical decisions for others?

In addition to qualitative comments, five other factors were analyzed; these include age, gender, religious preference, education level, and respondent's occupation. Spearman correlation coefficients were computed for age, education level, and occupation in relation to each of the seven scenarios. Gender and religious preference were analyzed employing contingency coefficients.

Age of the respondent was statistically significant across all seven scenarios (see Table 5). The older the respondent, the more likely he or she was to choose nutrition only for every situation ($p \leq .05$), including for the child. Younger respondents were more likely to choose full CPR for everyone.

Level of education was significant in only two of the seven scenarios: options for self and for one's co-worker. Higher education is related to choosing nutrition only for self and a middle-aged co-worker ($p \leq .05$) but is not related to any other groups, including the unknown person who is also described as middle-aged.

Respondent occupation was found to be significant in only one scenario, that of the middle-aged co-worker (Spearman correlation = .2281, N=150, $p \leq .002$). However, further analysis using age as a co-variate found no relationship between occupation and life support choices.

Religious preference of the respondent had no relationship to life support options chosen in any of the scenarios. Likewise, gender of the

respondent was not related to his or her decisions regarding life support for others.

Qualitative Factors

In all, each of 151 respondents was asked to make a life support choice for each of seven different scenarios, for a total of 1057 responses. Additionally, they were asked to list factors which shaped their particular decision in each case. From this large pool of potential responses, only 15 different reasons (including none or blank) emerged as the basis for the life support choice. These are listed in Table 7.

For each of the seven scenarios, a one way ANOVA was computed, and post-hoc analysis was performed using the Scheffe test. For each of the following results, $p \leq .05$.

In situation one (spouse), people who chose factors 2, 9, 10, and 13 (no quality of life, same as self, patient's guessed preference, physician statements) tended to choose nutrition only, whereas those reporting factors 3, 4, and 11 (no chance to live yet, personal feelings, chance of miracles) chose full life support for their spouse.

For situation two (child) the same factors (3, 4, 11) were listed as the basis of a full CPR choice, while 2 and 13 were stated as the basis of the nutrition only option. As previously reported, this scenario was the only one where most respondents chose full life support over the other options.

Situation three describes the elderly parent. Again, factors indicating personal feelings and potential for contribution were linked to full CPR, while long life, no quality of life, and the parent's guessed preference were related to providing only nutrition.

The situation regarding one's elderly neighbor (four) also divided respondents. Full CPR was chosen by those who had moral or philosophical

grounds, as well as hope for a miracle. Nutrition only was chosen by those who thought the neighbor had lived a long life and had no potential quality of life.

The co-worker was given nutrition only by those who felt he or she had no potential for quality of life, listed money as a decisional factor, and believed they knew what the co-worker would want. Conversely, those who hoped for a miracle or stated moral grounds for their choice provided their co-worker with full CPR.

Fewer factors were cited when making decisions for an unknown person (situation six). The pattern of choice, however, was consistent as in previous scenarios. Morality/philosophy and the chance for a miracle were cited as reasons for full CPR. Nutrition only was chosen by those who believed the person had no potential quality of life.

Decisions for self (situation seven) were consistent with decisions for others. Full CPR was chosen by those who felt they had not had a chance to live yet, who had religious grounds, or who hoped for a miracle. Nutrition only was chosen by those who felt there was no potential for quality of life and who did not want to be a burden to their families. Interestingly, religious teaching was significant only as a factor in decisions for self but not for others.

In conclusion, certain factors appear to be related to specific life support choices. Factors expressing hope, personal feelings, morality and potential contribution were related to full CPR. Perceived lack of quality of life, assumption of the patient's preferences and belief in the physician's stated prognosis were related to less aggressive life support (nutrition only).

Table 1

Social Desirability Scale

Spearman Rank Correlations

Full Scale Situation	Correlation	N	Significance
1. Spouse	-.3209	149	.000
2. Child	-.3190	147	.000
3. Parent	-.2560	150	.001
4. Neighbor	-.2588	149	.001
5. Co-worker	-.2447	150	.001
6. Unknown	-.3150	149	.000
7. Self	-.3094	150	.000
Religiosity Subscale Situation			
1. Spouse	-.2770	149	.000
2. Child	-.2386	147	.002
3. Parent	-.2520	150	.001
4. Neighbor	-.2709	149	.000
5. Co-worker	-.1854	150	.012
6. Unknown	-.2762	149	.000
7. Self	-.2599	150	.001

Knowledge	Correlation	N	Significance
Subscale			
Situation			
1. Spouse	-.2725	149	.000
2. Child	-.1901	147	.011
3. Parent	-.2181	150	.004
4. Neighbor	-.2071	149	.006
5. Co-worker	-.2591	150	.001
6. Unknown	-.1792	149	.014
7. Self	-.2139	150	.004
Attachment			
Subscale			
Situation			
1. Spouse	.0108	149	.448
2. Child	-.0704	147	.198
3. Parent	.-633	150	.221
4. Neighbor	.0808	149	.164
5. Co-worker	.0866	150	.146
6. Unknown	-.0440	149	.297
7. Self	-.0476	150	.281

Mean Scores on Social Desirability Scale

Variable	Mean	SD	Minimum	Maximum
Knowledge	-1.16	3.89	-11	8
Attachment	1.73	3.08	-10	8
Religiosity	14.64	3.61	4	20
Full Scale	15.21	6.09	-2	29

Table 2

Social Desirability Scale

Correlation Matrix

		Attachment	Knowledge	Religiosity	Full Scale
Attachment	Correlation		.0442	.0719	.5775
	N		151	151	151
	Significance		p = .295	p = .190	p = .000
Knowledge	Correlation	.0442		-.1159	.5920
	N	151		151	151
	Significance	p = .295		p=.078	p = .000
Religiosity	Correlation	.0719	-.1159		.5556
	N	151	151		151
	Significance	p = .190	p = .078		p = .000
Full Scale	Correlation	.5775	.5920	.5556	
	N	151	151	151	
	Significance	p = .000	p = .000	p = .000	

Table 3

Respondent Demographics

	Mean	SD	Range
Age	38.14	15.94	18-81
Number Children	1.21	1.45	0-7
Number in Family > 18	2.58	1.37	0-9
Number in Family < 18	.66	.93	0-4

Education Level Attained	Frequency	Percent
High School	12	7.9
Some College	75	49.7
Associate Degree	20	13.2
Bachelor's Degree	24	15.9
Master's Degree	10	6.6
Ph.D/Professional	10	6.6
TOTAL	151	100
Ethnicity		
African American	12	7.9
Hispanic/Latino	1	0.7
Pacific Islander	1	0.7
Caucasian	130	86.1
Native American	7	4.6
TOTAL	151	100

Gender	Frequency	Percent
Male	43	28.5
Female	108	71.5
TOTAL	151	100
Occupation		
Business/Professional	50	33.1
Office/Technical	42	27.8
Laborer	7	4.6
Disabled	1	0.7
Student	51	33.8
TOTAL	151	100
Relationship Status		
Married	82	54.3
Divorced	15	9.9
Separated	1	0.7
Co-Habiting	8	5.3
Widowed	1	0.7
Never Married	44	29.1
TOTAL	151	100

Religious Preference	Frequency	Percent
Blank	9	6
Protestant/Christian	117	77.5
Catholic	10	6.6
Jewish	1	0.7
None	8	5.3
Non-Denominational	6	4.0
TOTAL	151	100
Perceived Mental Health		
Excellent	61	40.4
Good	82	54.3
Fair	8	5.3
Poor	0	0
TOTAL	151	100
Perceived Physical Health		
Excellent	40	26.5
Good	99	65.6
Fair	12	7.9
Poor	0	0
TOTAL	151	100

Table 4

Correlation of Patient Age with Life Support Option

Situation	Correlation	N	Significance
1. Spouse	.3146	141	.000
2. Child	.1106	138	.098
3. Parent	.2988	146	.000
4. Neighbor	.2183	137	.005
5. Co-worker	.1138	142	.089
6. Unknown	.0591	126	.255
7. Self	.2686	147	.001

Table 5

Spearman Correlation Coefficients: Age of Respondent with Each of Seven Scenarios

Situation	Correlation	N	Significance
1. Spouse	.2262	149	.003
2. Child	.1630	147	.024
3. Parent	.1549	150	.029
4. Neighbor	.1577	149	.027
5. Co-worker	.1853	150	.012
6. Unknown	.1628	149	.024
7. Self	.1669	150	.021

Table 6

Qualitative Responses Listed as Factors in Life Support Decisions

Factor	Description
0	No reason given or blank
1	Person has had a long life
2	No potential for quality of life or do not want person to suffer
3	Person has the potential to contribute or no chance to live yet
4	Love and personal feelings
5	Money
6	Philosophical or moral issue
7	Religious teaching
8	Do not want to be a burden to others
9	Same decision as I would make for myself
10	"I know this is what they would want" (includes guesses and reports of conversations)
11	Doctors can be wrong or chance of a miracle
12	I don't know the person or their preference
13	The physician stated there is no chance of recovery
14	There is no one to care for them if they live

Table 7

Age of Patient in Scenario

Situation	Mean	SD	Minimum	Maximum
1. Spouse	43.27	16.90	18	94
2. Child	15.04	11.99	1	76
3. Parent	72.68	14.50	19	106
4. Neighbor	75.29	11.63	22	98
5. Co-worker	43.93	10.01	21	79
6. Unknown	49.14	12.01	26	106
7. Self	43.38	18.40	18	106*

*Estimated age at death for some subjects.

Table 8

Frequency of Reason for Life Support Choice

Reason	Spouse	Child	Parent	Neighbor	Co-Worker	Unknown	Self
0	10	13	15	21	23	25	14
1	1	1	9	24	1	2	3
2	32	35	27	19	22	35	38
3	14	22	6	4	16	11	18
4	19	27	20	3	2	3	1
5	2	1	2	2	4	6	2
6	1	6	7	23	25	34	10
7	8	11	6	8	8	6	10
8	1	1	0	0	0	1	36
9	3	2	2	5	6	2	1
10	37	6	49	28	25	4	7
11	16	21	5	8	13	12	8
12	0	0	0	1	3	6	0
13	7	4	3	4	2	3	2
14	0	0	0	1	1	1	0
999	0	1	0	0	0	0	1

999 represents missing data

Table 9

Frequency of Responses on Social Desirability Scale

Question	All No Answers	Uncertain	All Yes Answers
Consider self religious	12	8	131
All life is sacred	9	9	133
There is life after death	6	19	126
Money is a factor in life support	92	15	44
Family is most important	8	4	139
Right to own decisions	18	7	126
Always ask family advice	61	8	82
Career is most important	108	14	29
TV death is realistic	108	22	21
Have made life support decision	122	0	29
Living wills are only a guide	94	16	41
I have/plan to have a living will	30	19	102

APPENDIX D

HUMAN SUBJECTS RESEARCH APPROVAL

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
HUMAN SUBJECTS REVIEW

Date: 09-25-96 **IRB#: HE-97-013**

Proposal Title: ETHICAL DILEMMA RESOLUTION: IS AGE A FACTOR IN LIFE SUPPORT CHOICES

Principal Investigator(s): Joseph A. Weber, Jeri Katherine Cooper

Reviewed and Processed as: Exempt

Approval Status Recommended by Reviewer(s): Approved

ALL APPROVALS MAY BE SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING, AS WELL AS ARE SUBJECT TO MONITORING AT ANY TIME DURING THE APPROVAL PERIOD.
APPROVAL STATUS PERIOD VALID FOR ONE CALENDAR YEAR AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL.
ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Reasons for Deferral or Disapproval are as follows:

Signature: _____ Date: October 3, 1996
Chair of Institutional Review Board

VITA

Jeri Katherine Cooper

Candidate for the Degree of

Doctor of Philosophy

Thesis: ETHICAL DILEMMA RESOLUTION: IS AGE A FACTOR IN LIFE SUPPORT CHOICES

Major Field: Human Environmental Sciences

Biographical:

Education: Graduated from Memorial High School, Tulsa, Oklahoma, May, 1972; attended Oral Roberts University, Tulsa, Oklahoma, Tulsa Junior College, Tulsa, Oklahoma, the University of Iowa, Iowa City, Iowa, 1972-1974; received Bachelor of Science in Food, Nutrition and Institution Administration, Oklahoma State University, Stillwater, Oklahoma, December, 1976; received Master of Science in Food, Nutrition and Institution Administration, Oklahoma State University, July, 1978. Attended Texas Woman's University, Denton, Texas, 1981-1982. Received Bachelor of Science in Nursing, The University of Tulsa, Tulsa, Oklahoma, May, 1984. Completed the requirements for the Doctor of Philosophy Degree at Oklahoma State University, Stillwater, Oklahoma in December, 1997.

Experience: Clinical Manager, Oncology Unit; Education Specialist; House Supervisor, Saint Francis Hospital, Tulsa, Oklahoma, 1992-1995. Graduate Research Associate, Oklahoma State University, Department of Family Relations and Child Development, 1994-1996.